

Adults with autism spectrum disorder: Diagnostic assessment, personality (pathology), and psychotherapy

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Richard Vuijk
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**Adults with autism spectrum disorder:
Diagnostic assessment, personality (pathology), and psychotherapy**

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Faculteit der Maatschappij- en Gedragwetenschappen

*Dankt, dankt nu allen God met hart en mond en handen,
Die grote dingen doet hier en in alle landen,
Die ons van kindsbeen aan, ja, van de moederschoot,
Zijn vaderlijke hand en trouwe liefde bood.*

*Die eeuwig rijke God moge ons reeds in dit leven
een vrij en vrolijk hart en milde vrede geven.
Die uit genade ons behoudt te allen tijd,
is hier en overal een Helper Die bevrijdt.*

*Lof, eer en prijs zij God Die troont in 't licht daarboven.
Hem, Vader, Zoon en Geest moet heel de schepping loven.
Van Hem, de ene Heer, gaf het verleden blijk,
het heden zingt Zijn eer, de toekomst is Zijn rijk.*

Dichter: Martin Rinckart (1586-1649)

Vertaling: Jan Wit (1914-1980)

Liedboek voor de Kerken (1973). *Gezang 44*. Boekencentrum Uitgevers.

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General Introduction



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1.1 Autism spectrum disorder

1.1.1 The beginning: A brief history of the autism construct

The conditions, challenges, and problems we nowadays call autism spectrum disorder (ASD), were initially only observed in infants and children in the 1940s. In Anglo-Saxon literature, the first cases of ASD were described by the psychiatrists Leo Kanner (1943) and Hans Asperger (1944), although Eugen Bleuler (1911), psychiatrist, was the first to use the name *autism* to describe a state of insulation from reality, detachment, and social withdrawal in adults with schizophrenia (Robinson 2017). Kanner observed children who were severely affected and characterized by ‘an inability to relate themselves in the ordinary way to people and situations from the beginning of life’ (Kanner 1943, p. 242). Kanner used the words *early infantile autism*, an inborn disorder where infants were cut off from the social world, with an insistence on sameness and a resistance to change. Asperger used the word *autism* (‘frequently translated as ‘autistic psychopathy’ but probably better translated as ‘autistic personality disorder’, Volkmar et al. 2014, p. 17), suggesting an obvious similarity to Kanner’s description, for boys characterized by social impairment and verbal precocity. Asperger (1944) was the first to mention the autistic character of adults, i.e., the parents of the children he observed.

Since these first observations many thousands of studies examining children with ASD have been published in contrast to only a tiny proportion of studies of adults with ASD (Howlin, 2014). Although research on adults with ASD is increasing, still many aspects of adult ASD are unknown or not well understood.

1.1.2 DSM ASD, prevalence, etiology, gender

ASD, the spectrum concept first proposed by Lorna Wing (1981; 1996), is considered as a lifelong persistent neurodevelopmental disorder of specific behavioral aspects with an early childhood onset. ASD first appeared as pervasive developmental disorder (PDD) in 1980 in the *Diagnostic and Statistical Manual of Mental Disorders Third Edition* (DSM-III; American Psychiatric Association 1980). In the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision* (DSM-IV-TR; American Psychiatric Association 2000), the core characteristics emphasize qualitative challenges in social interaction and in communication, restricted repetitive and stereotyped patterns of behaviors and interests, and need for a predictable and stable environment, classified as autistic disorder (AD), Asperger’s disorder (AS), and pervasive developmental disorder not otherwise specified (PDD-NOS). These three are all considered to be ‘autism spectrum disorders’. However, the *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* (DSM-5; American Psychiatric Association 2013) definition of ASD changed considerably with the aim to increase the specificity of the diagnosis, as well as to identify a population of individuals

that overlaps and differs compared to DSM-IV-TR (Bennett & Goodall 2016; Harstad et al. 2015). The core characteristics are still persistent challenges in social communication and social interaction over a variety of contexts and a tendency for repetitive patterns of behavior, interests, or activities, with the addition of sensory issues including hyper- or hyporeactivity to stimuli or unusual interest in stimuli (American Psychiatric Association 2013, p. 50). In the DSM-5 the classification has become autism spectrum disorder (ASD). Three current severity levels based on the core characteristics are distinguished: (1) requiring support, (2) requiring substantial support, and (3) requiring very substantial support. ASD can be specified with or without accompanying intellectual impairment, and with or without accompanying language impairment. ‘Symptoms must be present in the early developmental period, but may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies later in life’ (American Psychiatric Association 2013, p. 50).

The just mentioned lifelong condition, ASD starting when children are infants or toddlers continuing into adulthood, has been confirmed by the prevalence rates of at least 1% across all ages in the general population (Brugha et al. 2011; Brugha et al. 2016; CDC 2014; Presmanes Hill et al. 2014; Shattuck et al. 2007). For children there is a recent upward adjustment ranging from 1.68% (Baio et al. 2018) to 2.47% (Xu et al. 2018), partly due to an unstandardized autism survey methodology (Fombonne 2018). For adults in the United States a national and state prevalence of approximately 2.2% has been estimated (Dietz et al. 2020). The etiopathogenesis of ASD is unclear, but gene variants and gene-environment interactions have been identified as two of the main causes of the pathophysiology of ASD characteristics (see Waterhouse et al. 2016).

Without co-occurring intellectual disability the male-to-female ratio is 3.4:1 (Fombonne 2005; 2009). The sex issue in ASD has been topic of many research studies, such as on the influence of sex on diagnostic evaluation of ASD (Wilson et al. 2016). A systematic review and meta-analysis showed no major differences between males and females in communication and social behavior (Van Wijngaarden et al. 2014). Nonetheless some are arguing that there is a specific female ASD phenotype with lower restricted interests, higher irritability, and externalizing behavior as compared to the male ASD phenotype (Frazier et al. 2014). The phenomenon of camouflaging and pretending to be ‘normal’ seems one of the key elements of the female ASD phenotype (Bargiela et al. 2016). This camouflaging seems to be significantly associated with psychological distress and functional challenges (Beck et al. 2020), and is also one of the perceived barriers to ASD diagnosis for females (Lockwood Estrin et al. 2021). However, overall, there is still ‘no consensus on whether men and women with ASD present differently’ (Ferri et al. 2018, p. 8).

1.1.3 Heterogeneous and dimensional ASD

The ASD concept is not only a distinct dichotomous DSM category (categorical approach): ASD is also viewed as heterogeneous and dimensional. Its heterogeneity ranges from the phenotypic autism spectrum to brain structures and etiopathogenesis (Jeste & Geschwind 2014; Martinez-Murcia et al. 2017; Mottron & Bzdok 2020). Different dimensional perspectives on the ASD concept are: (1) the *broader autism phenotype* (BAP), (2) the evolution of the expanded ASD phenotypes and the theory of ‘ordinary’ or ‘invisible’ autism (Frigaux et al. 2021), (3) the *Adult Autism Subthreshold Spectrum* (AdAS) model (Dell’Osso et al. 2016; 2018), and (4) neurodiversity and the autism predicament model (Anderson-Chavarria 2021). In all these theories and approaches we see a shift in the diagnostic threshold (over time): individuals with less severe autistic behaviors are more and more diagnosed with ASD (Whitehouse et al. 2017).

(1) In the early 90s (but already mentioned by Kanner and Asperger in the 1940s), the BAP, a collection of sub-diagnostic and subtle autistic traits more common in families of individuals with ASD than in the general population, has been suggested (Piven et al. 1990; Rubenstein & Chawla 2018). The ASD phenotype extends beyond DSM-IV (Bolton et al. 1994) and DSM-5 ASD. No longer exclusive for family members of people with ASD, the BAP model expands more and more into the general population (Dovgan & Villanti 2021; Landry & Chouinard 2016) and in individuals affected by other psychiatric disorders such as borderline personality disorder (PD) and bipolar disorder (Dell’Osso et al. 2021).

(2) What follows, is the notion of ‘ordinary’ or ‘invisible’ autism, ‘a proposed hypothesis to define attenuated or compensated non-prototypical autistic phenotypes, increasingly frequent, and with fewer ‘extraordinary’ phenomenological expressions than the classic cases of autism’ (Frigaux et al. 2021, p. xxx.e2).

(3) The AdAS model, developed by Dell’Osso et al. (2016; 2018), is a novel comprehensive psychopathological theory with a transnosographic dimension broadening and redefining the DSM-5 dimensional approach. ‘The AdAS model includes threshold-level manifestations, mild and atypical symptoms of ASD, gender-specific features, behavioral manifestations, and personality traits associated with ASD’ (Dell’Osso 2018, p. 118).

(4) Neurodiversity and the autism predicament model consider ASD not as pathological but as natural and valuable human variation and as a predicament of individual experiences (Anderson-Chavarria 2021): ASD not as impairing or as a diagnosis but as a cognitive style or personality type (see Happé & Frith 2020), and ASD as a social category, disabled in social contexts, real and valuable for political and ethical reasons (Chapman 2020; 2021). Advocates of this perspective consider the expertise of people with ASD to be valued and needed in partnerships in ASD intervention research and practice (see Leadbitter et al. 2021).

In this thesis, I follow the DSM-IV-TR and DSM-5 ASD classification: our studies were carried out in a mental health institute specialized in psychodiagnostic assessments and interventions for children, adolescents, and adults with a broad range of mental disorders including ASD that routinely uses the DSM classification. In this thesis, I chose to use person-first language (i.e., a person with ASD), putting the person before the diagnostic classification instead of identity-first language (an autistic person) to emphasize a person’s identity instead of a DSM-classification. In Dutch health care using person-first language instead of identity-first language for people with mental disorders is still common, but the different perspectives and the growing general preference for identity-first language worldwide are acknowledged as well (Botha et al. 2021; Bury et al. 2020; Vivanti 2021).

1.2 ASD in adults

The transition from childhood and adolescence to adulthood seems to be a real challenge for individuals with ASD (Thompson et al. 2018). The prognosis is generally poor, with a minority of adults with ASD having a good outcome and living independently, almost half still living with their parents, fewer than half having employment (generally low level and poorly paid) or full-time higher education, and only a few have social connectedness and intimate relationships (Anderson et al. 2018; Howlin & Moss 2012; Howlin et al. 2013). A study investigating prevalence rates of mental health conditions and physical disabilities in a whole country population of adults with and without ASD found an odd ratio of 8.6 (95% confidence interval 8.2 to 9.0) for co-occurring general mental disorders (Rydzewska et al. 2018). Adults with ASD are affected with a high burden of psychiatric comorbidity (Hossain et al. 2020), ranging from 59% suffering from psychiatric disorders and symptoms to 79% meeting criteria for a psychiatric disorder at least once in their lives, with depression and anxiety as most common (Buck et al. 2014; Croen et al. 2015; Kentrou et al. 2021; Lever & Geurts 2016). For a complete and current overview of co-occurring psychiatric conditions in individuals with ASD including case studies and treatment approaches, we refer to the *Oxford Handbook of Autism and Co-Occurring Psychiatric Conditions* (White et al. 2020). The ASD difficulties and challenges in social relationships, employment, and co-occurring psychiatric conditions are high risk factors for poor quality of life, physical health problems, significant functional impairments, and low life satisfaction (Barneveld et al. 2014; Findon et al. 2016; Forde et al. 2021; Mason et al. 2019; Schmidt et al. 2015). Higher intellectual functioning appears to be a protective factor against a poor outcome (Mason et al. 2020), and the picture of those with average to high intellectual abilities seemed more positive than previously found in research (Scheeren et al. 2021).

As we will see next, there is an urgent need for improvement of the accuracy and timeliness of ASD assessment in adults and the implementation of specific interventions and support for adults with ASD with or without general mental disorder comorbidity (Alexander & Farrelly 2019; Camm-Crosbie et al. 2019; Jones et al. 2014; Keller et al. 2020; Rogers et al. 2015; Rutherford et al. 2016; Van Schalkwyk et al. 2015; Volkmar & Wolf 2013). Optimizing their outcomes and improving their symptom management are needed. This thesis contributes to this need by focusing on diagnostic assessment (Chapter 2), personality (pathology) (Chapters 3, 4, and 5), and psychotherapy (Chapters 6, 7, and 8).

1.2.1 Diagnostic assessment of ASD in adults

There is an increased recognition and first-time diagnosing of ASD in adulthood especially in individuals without intellectual disability (White et al. 2011). Referral reasons as social problems, and feelings of anxiety and depression are the most common among them (Geurts & Jansen 2012). Four independent studies showed that most adults will be diagnosed with ASD when they are between 30 and 45 years of age (Geurts & Jansen 2012; Happé et al. 2016; Jones et al. 2014; Lehnhardt et al. 2012). Diagnosing ASD in adults seems to be a lengthy process with a mean duration of 159.2 days between referral and receiving a diagnosis (McKenzie et al. 2015). The assessment is complex and challenging because of a number of factors as: (1) comorbidity and differential diagnosis issues; (2) the compensating possibilities of a high intelligence for challenges; (3) an available structured support system; (4) the unavailability of parental and partner information; and (5) the camouflaging of the social disability (Bastiaansen et al. 2011; Huang et al. 2020; Hull et al. 2020; Lai & Baron-Cohen 2015), or in other words, when individuals show 'ordinary' and 'invisible' non-prototypical autistic functioning (Frigaux et al. 2021). Moreover, many (non-specialist) healthcare professionals show a lack of awareness and understanding of ASD, clinical assessment skills in adult ASD, and have poor communication with individuals with ASD (Au-Yeung et al. 2019; Brugha et al. 2011). Fear of not being believed by professionals seems to be the most frequently occurring and most severe barrier that hinder accurate diagnosis and support (Lewis 2017). For a valid ASD diagnosis the professional needs to have a combination of clinical assessment skills, expertise with standardized testing, awareness of ASD in adults, and offering a trustful relationship with individuals with ASD (Lewis 2017; Wigham et al. 2019).

The number of diagnostic assessment instruments for adults suspected to meet criteria for ASD is growing, but evidence in their validity and reliability is either lacking or limited according to several review studies (Baghdadli et al 2017; Hirota et al 2018; Stoesz et al. 2011). A clinical judgment by experienced clinicians accompanied by standardized diagnostic instruments seems to be the best way for validly and reliably diagnosing ASD in children (Lord et al. 2006; Wiggins et al.

2015). For diagnosing ASD in adults we expect this diagnostic process to be the same. Standardized ASD assessment instruments seems to be very or quite helpful as reported by practitioners from child and adult services (Rogers et al. 2015). The *NICE guideline on recognition, referral, diagnosis, and management of adults on the autism spectrum* (NCCMH 2012) recommends to combine the use of the *Autism Diagnostic Interview – Revised* (ADI-R; Lord et al. 1997) as a semi-structured assessment of developmental history and the *Autism Diagnostic Observation Schedule – Generic* (ADOS-G; Lord et al. 2000) as a standardized observational measure, both as best practice process and procedure for diagnosing ASD in adults. The *Dutch guideline on diagnosis and treatment of adults on the autism spectrum* (Kan et al. 2013) does not recommend the ADI-R and the ADOS-G. The Dutch guideline (Kan et al. 2013) concludes ADI-R too time consuming in administration, and ADOS-G being inadequate for intelligent people, and for those who are camouflaging the social difficulties (Bastiaansen et al. 2011; Lai et al. 2011; Langmann et al. 2017; Lord et al. 2000). Their advice, when an ASD assessment is indicated, is to integrate several sources of information from assessment in-person interviews, in-person observation to a detailed developmental history interview with the adult's childhood parents/caregivers or someone who knew the adult very well in childhood when available. In the end, we define a clinical ASD diagnosis by describing core characteristics in terms of DSM (or equivalent) criteria, so to systematically assess and quantify these criteria the use of a (semi-) structured DSM-5 interview for ASD might be helpful (see Chapter 2).

1.2.2 Personality (pathology) in adults with ASD

Temperament, character, and personality

Everyone is different and we all have our own unique personality. Allport (1937, p. 48), one of the founders of personality psychology, defined personality as 'the dynamic organization within the individual of those psychophysical systems that determine his unique adjustments to the environment'. Over the years diverse and different perspectives on the conceptualization of personality have emerged and have always coexisted (Cloninger 2009). One of the most current used perspectives on personality is Cloninger's biopsychosocial theory of personality based on the assumption that personality involves (four) temperament dimensions and (three) character dimensions (Cloninger 1987; Cloninger et al. 1993). Temperament refers to consistent individual differences in behavior at a strongly genetic and biological base and relatively independent of learning (Strelau 1983). Cloninger's temperament dimensions, measuring individual differences in basic emotional drives are Novelty Seeking, Harm Avoidance, Reward Dependence, and Persistence (Cloninger et al. 1993). Character reflects a person's goals and values developed over the lifespan

and representing a person's style of mental self-government (Cloninger 2010). Cloninger's character dimensions include Self-Directedness, Cooperativeness, and Self-Transcendence (Cloninger et al. 1993).

Personality pathology and personality disorder

Personality pathology refers to maladaptive personality traits (Tackett et al. 2009). Difficulties in temperament and deficits in character maturation interacting with negative factors of the environment (e.g. affective deprivation, insecure attachment, abuse) are a potential risk for the development of maladaptive personality traits and PDs. A PD is 'enduring, pervasive, inflexible, and time-stable in inner experiences and behaviors that deviate markedly from the expectations of the individual's culture, resulting in distress and/or impairment' (American Psychiatric Association 2013, p. 646).

Personality (pathology) in adults with ASD

People with an ASD are of course, like everybody else, human beings with a unique personality with strengths and weaknesses. They show a great diversity in intelligence, language development, social interaction styles (SISs), severity of ASD characteristics, comorbid problems as well as personality (pathology). This wide variety of presentations contributes to heterogeneity amongst them (Lai et al. 2013), and is supposed to be a complicating factor in deciding what will be the best services and treatments for them (Masi et al. 2017; Rutter & Schopler 1992). Therefore, we need to reduce the heterogeneity of the autism spectrum into meaningful, more homogeneous categories, already proposed by researchers and clinicians alike (e.g., Barnoux et al. 2020; Begeer et al. 2015; Bishop et al. 2016). One of the three foci of this thesis is exploring personality pathology and its association with SISs, two concepts that play a role in the heterogeneity amongst people with ASD (see Paragraph 1.3, and Chapters 3, 4, and 5).

Both ASD and PD have difficulties in interpersonal functioning in common with a stable long during pattern. ASD, a neurodevelopmental disorder, affecting social interaction and communication, usually appears in the early developmental period of life, whereas for a PD possible negative factors (like abuse, inadequate parenting) appearing in early childhood combined with neurobiological and genetic factors play a part in the development of a PD. Each PD has its own kind of interpersonal difficulties. For example, when having a paranoid PD, interpersonal functioning is disturbed by 'a pervasive distrust and suspiciousness of others such that their motives are interpreted as malevolent' (American Psychiatric Association 2013, p. 649). When having a dependent PD interpersonal functioning is disturbed by 'a pervasive and excessive need to be taken care of which leads to submissive and clinging behavior and fears of separation' (American Psychiatric Association 2013,

p. 675). Difference and overlap between ASD and PD are more and more topics of research. Adults with ASD evaluate their reading emotions as more impaired, and their intrapersonal functioning as better than adults with PD (Duijkers et al. 2014). Adults with ASD use more maladaptive and less adaptive interpersonal emotion strategies than adults with borderline PD (López-Pérez et al. 2017). In two studies, adults with borderline PD reported more autistic traits than general population controls (Dell'Osso et al. 2018; Dell'Osso et al. 2021) whereas in another study adults with ASD and comorbid borderline PD score higher on autistic traits than adults with borderline PD only (Dudas et al. 2017). Empathy, mentalization, and theory of mind have been suggested as possible overlapping constructs between borderline PD and ASD (Vegni et al. 2021). A review and meta-analysis showed superficial overlap between ASD and borderline PD with a general low quality of empirical evidence (May et al. 2012). Overlap between autistic traits and schizotypal PD traits was found in adolescents with ASD (Barneveld et al. 2011). A study by Stanfield et al. (2017) showed that social cognition deficits in ASD and schizotypal PD are the result of different brain mechanisms. In an exploratory study aiming to investigate the overlap between obsessive-compulsive PDs and ASD traits in obsessive-compulsive disorder individuals, the obsessive-compulsive PD was strongly associated with ASD (Gadelkarim et al. 2019).

Increasing numbers of studies have examined ASD and comorbid personality pathology (see Chapters 3 and 4). Several studies examining temperament and character assessed with the *Temperament and Character Inventory* (TCI; Cloninger et al. 1994) in adults with ASD found low scores on Novelty Seeking, Reward Dependence, Self-directedness, Cooperativeness, and high scores on Harm Avoidance and Self-transcendence (Anckarsäter et al. 2006; Helles et al. 2016; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012). A meta-analysis of Big-Five personality traits in adults with ASD showed negative associations between ASD characteristics and Openness to Experience, Conscientiousness, Extraversion, Agreeableness, and emotional stability (Lodi-Smith et al. 2019). PD comorbidity in adults with ASD seems to range from 48% to 62% (Hofvander et al. 2009; Lugnegård et al. 2012).

The focus in personality research in individuals with ASD is often on the weaknesses, but interest in studying personality strengths is growing. Strengths of the personality profile of individuals with ASD are straightforwardness (frankness in expression), modesty and compliance, reliability, orderliness (well organized, thinking things through before acting, taking moral obligations very seriously), and openness to a variety of intellectual stimuli (Strunz et al. 2015). A study examining character strengths in adults with ASD found intellectual strengths (open-mindedness, creativity, and love of learning), authenticity, and fairness as the most frequent character strengths (Kirchner et al. 2016). In a worldwide survey, studying the functioning and disability in ASD across the lifespan honesty, loyalty,

attention to detail, and creative talents were provided by experts as positive personal characteristics and ASD-related functioning (De Schipper et al. 2016). A study assessing levels of self-insight in individuals with ASD suggested significant levels of understanding into their own personality as well as a similar level of self-insight compared to non-ASD individuals (Schriber et al. 2014). A study examining meta-accuracy showed no difference on self-perception in personality traits between adults with ASD and non-autistic adults (Sasson et al. 2018). Due to the adequate levels of self-insight and self-perception, self-reports assessing personality (pathology) in adults with ASD have been found valid and reliable (Hesselmark et al. 2015).

The relation between ASD and personality (pathology) is largely unknown and so far not yet clearly determined. The associations between ASD and personality seem at least partly due to genetic effects (Kerekes et al. 2013). A study analyzing the relation between autistic traits and experience seeking in a general population sample of adults demonstrated an inverse relationship between autistic traits and experience seeking at a phenotypic as well genetic level (Romero-Martínez et al. 2016). A study exploring the genetic and environmental influences between ASD characteristics and temperamental and character dimensions in adults from a population-based twin register suggested a sharing of common genetic and environmental etiological factors between ASD characteristics and personality dimensions (Picardi et al. 2015). A study examining the characteristic ASD SISs according to the *Wing's Subgrouping Scheme* developed by Wing and Gould (1979) in children and adolescents showed developmental stability in the passive and active-but-odd SISs, suggesting overlap with temperament (Scheeren et al. 2020). So far the studies of SISs ranging from social aloofness to awkward social approaches as perceived by non-autistic others (Shah 1988; Wing & Gould 1979) focused mainly on children and adolescents. Whether these SISs can also be distinguished in adults with ASD, and how this relates to the presence of DSM-5 PDs has not yet been explored (see Chapter 5).

Studying personality (pathology) in adults with ASD serves to enhance our understanding of 'risk factors, etiology, pathophysiology, phenomenology, illness course, and treatment response' (Kotov et al. 2017, p. 21), as well as the heterogeneity of ASD, protective factors, and a more comprehensive perspective on the person behind the disorder.

1.2.3 Psychotherapy for adults with ASD

Over the last 10 years, psychotherapy is more and more considered to be a possibility for adults with ASD with and without comorbid psychiatric disorders, but a lack of therapist knowledge or expertise in ASD, and not tailoring treatment to the needs of people with ASD have been reported as the most common perceived barriers for people with ASD to access psychological treatment (Adams & Young 2021). From the perspective of individuals with ASD, negative treatment experiences (being excluded

from mental health services, inappropriate treatment, therapists with a lack of understanding, and knowledge of ASD) as well as positive treatment experiences (benefitting from a tailored treatment with positive effects on well-being) have been reported (Camm-Crosbie et al. 2019; Lipinski et al. 2019). A broad and deep understanding of the way individuals with ASD communicate and appropriate adaptations to interventions are needed (Cooper et al. 2018; Koenig & Levine 2011). 'The psychotherapist needs to be fluent in 'Aspergerese'; in other words, to recognize that autism is a different way of thinking – almost a different culture – and be able to translate the concepts and components of the therapy to someone with this different way of thinking' (Gaus 2019, p. ix). Adaptations to interventions include the use of written and visual information, behavior change over a cognitive approach, setting clear expectations of the interventions, space for special interest, setting a realistic pace, using language effectively, and if necessary involving a partner, friend, or family member (Anderson & Morris 2006; Gaus 2019; Lipinski et al. 2019). In a university counseling center setting examining psychotherapy outcomes, students with ASD needed significantly more treatment sessions to achieve maximum improvement than students without ASD (Anderberg et al. 2017).

Systematic reviews exploring the effectiveness of treatment interventions for adults with ASD emerge more and more, and demonstrate the effectiveness especially for comorbid depressive and anxiety disorders. A critical review of cognitive behavioral therapy (CBT) suggested CBT to be helpful in decreasing comorbid mental health symptoms, but little evidence was found for increasing social and communicative functioning in adults with ASD (Binnie & Blainey 2013). However another review reported CBT including behavioral, cognitive, and mindfulness techniques to be moderately effective for comorbid anxiety and depressive symptoms in adults with ASD (Spain et al. 2015). Small to medium effect sizes were reported in a structured review of CBT when used to treat comorbid affective disorders as well as ASD characteristics in children, adolescents, and adults with ASD (Weston et al. 2016). A systematic review of treatment of depression in individuals with ASD (age range 8 to 65 years) showed generally poor evidence for effect and inconsistent results for CBT, but mindfulness interventions were found to be preliminary effective (Menezes et al. 2020). A review study investigating the effects of mindfulness interventions on adults with ASD indicated a reduction in anxiety, depression, and rumination, and an increased positive affect (Cachia et al. 2016). A systematic review found preliminary evidence for the effectiveness of traditional treatments of posttraumatic stress disorder in individuals with ASD (age range 6 to 45 years) (Rumball 2019). A structural review of psychosocial interventions targeting the specific ASD challenges like applied behavior analysis and social cognition training provided largely positive results for adults with ASD (Bishop-Fitzpatrick et al. 2013). A narrative analysis suggested group social skills interventions to be

effective for more social knowledge and understanding, a better social functioning, less loneliness, and a potential relief of comorbid mental health symptoms (Spain & Blainey 2015). Most review studies concluded quantity and quality limitations of the included treatment studies with an urgent need of methodologically rigorous and well-controlled studies. To my knowledge, studies examining PD treatment in adults with ASD and comorbid PD are lacking, despite the urgent need to investigate the effectiveness of PD interventions in these individuals (see Chapters 7 and 8).

1.3 Aims and outline of the present thesis

This thesis consists of three parts: (I) diagnostic assessment of ASD, (II) personality (pathology), and (III) psychotherapy.

Part I focuses on diagnostic assessment of ASD in adults. Chapter 2 deals with a study of the psychometric properties of a new diagnostic ASD instrument, the *Dutch Interview for Diagnostic assessment Autism spectrum disorder in adults* (NIDA) (Vuijk 2016; see Appendices 1 and 2). In this study, we examine the reliability and validity of the in-person current functioning part of the NIDA by measuring its interrater agreement, and convergent, incremental, and concurrent criterion-related validity in a Dutch sample of adult males without intellectual disability. We choose to compare the group of ASD participants not only with a group of general population participants without ASD, but also with a clinical group of PD participants without ASD. In this way we examine the suitability of the NIDA for clinical use and especially differentiation to conditions for which the differential diagnosis is considered to be clinically challenging.

Part II focuses on personality (pathology). Chapter 3 presents a systematic review of studies of temperament, character, personality pathology, and PDs in adults with ASD. This study provides a literature overview of how personality and its dimensions of temperament and character, as well as personality pathology and PDs have been studied in adults with ASD. Participant characteristics, types of personality (pathology) measures, statistical methods, and results are examined. Meta-analyses of temperament, character, and PDs are conducted. Chapter 4 reports on temperament and character dimensions in adult males with ASD. This study aims to explore temperament and character dimensions by reanalyzing a 2012 data set by individual case matching whereas the analyses in the 2012 publication (Vuijk et al. 2012) and previous temperament and character studies were based on generally norm group matching. This study seeks to test and strengthen previous findings. Chapter 5 presents a study aiming to explore atypical SISs, first described by Wing and Gould (1979), of adult males with ASD without intellectual disability and with

or without PD (traits) compared to males with PD without ASD and males from the general population. In this study, the associations between SISs and DSM-5 PD traits are examined for both adults with ASD as well as adults with PD.

Part III focuses on psychotherapy. Chapter 6 outlines a case example of a man with ASD and comorbid PD exemplifying the Schema Therapy (ST) approach as a treatment possibility for adults with ASD and comorbid PD. 'Do's and don'ts' for a therapist treating PD in people with ASD are given. Chapter 7 describes the protocol of our ST program for adults with both ASD and PD aiming to investigate whether ST with cognitive behavioral and experiential techniques will be effective for adults with both ASD and PD. Chapter 8 presents the results of the ST case series study of Chapter 7. Core beliefs, schema modes, PD traits, psychopathological symptoms, general mental disorders, and social responsiveness are examined.

Chapter 9, the general discussion, presents the summary of the main findings, and we discuss the strengths, limitations, and clinical relevance emerging from these studies. Recommendations for future research and key findings are given.

The studies in Chapters 2, 4, 5, and 8 were carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki, 2000). Approval for the studies in Chapters 2, 5, 7, and 8 was granted by the Ethics Committee of the University of Amsterdam, the Netherlands (Date: 04 April 2017/No.: 2017-CP-7839 - Chapters 2 and 5; and Date: 02 February 2016/No.: 2015-CP-6374 - Chapters 7 and 8), and for the study in Chapter 4 by the Medical Ethics Committee of Erasmus MC, Rotterdam, the Netherlands (Date: 24 July 2008/MEC-2008-221). The studies in Chapters 2 and 5 were registered in the Netherlands Trial Register on 04 May 2017 (NTR6391/ <https://www.trialregister.nl/trial/6219>). The study in Chapters 7 and 8 was registered in the Netherlands Trial Register on 01 April 2016 (NTR5788/ <https://www.trialregister.nl/trial/5653>). For the studies in Chapters 2 and 5 all participants took part in both studies.

Part I

Diagnostic Assessment



2

First psychometric properties of the Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adult males without intellectual disability

Richard Vuijk, Mathijs Deen, Arnoud Arntz, Hilde M. Geurts

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Abstract

For autism spectrum disorder (ASD) in adults there are several diagnostic instruments available with a need for consideration of the psychometric properties. This study aimed to conduct a first psychometric evaluation of a new diagnostic ASD instrument, the NIDA (Dutch Interview for Diagnostic assessment of ASD in adults) in 90 adult males without intellectual disability (age 18 to 65 years) in the Netherlands: 30 with ASD, 30 with a Personality Disorder, and 30 nonpatient controls. The interrater agreement ranged from .79 to 1.00, the convergent validity including sensitivity and specificity ranged from .76 to 1.00, and we observed an adequate concurrent criterion-related validity. These promising findings can serve as foundation for future psychometric NIDA studies in a more diverse population.

Author contributions

All authors contributed to the study conception and design. Material preparation and data collection was performed by Richard Vuijk. Data analyses were performed by Richard Vuijk and Mathijs Deen and checked by the rest of the authors. The first draft of the manuscript was written by Richard Vuijk, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

2.1 Introduction

Autism spectrum disorder (ASD) is typically considered as a neurodevelopmental condition with an early childhood onset and life time persistency of specific behavioural aspects. In the DSM-IV (American Psychiatric Association 2000), the core symptoms emphasize qualitative challenges in social interaction and in communication, and restricted repetitive and stereotyped patterns of behavior, classified as autistic disorder (AD), Asperger's disorder (AS), and pervasive developmental disorder not otherwise specified (PDD-NOS). These three are all considered to be 'autism spectrum disorders'. However, the DSM-5 (American Psychiatric Association 2013) definition of ASD changed considerably. The core symptoms are still persistent challenges in social communication and social interaction over a variety of contexts and a tendency for repetitive patterns of behavior, interests, or activities. However, the classification is now autism spectrum disorder (ASD) with three severity levels. This change in criteria has an impact on the ASD assessment toolbox, raising the question which instruments can be used to assess DSM-5 ASD. Until now, not a single autism-specific diagnostic instrument follows the complete DSM-5 decision-making rules for diagnostic classification (Evers et al. 2021). Thereby assessment tools for adult ASD are limited and, to the best of our knowledge, not a single in-person diagnostic DSM-5 interview for adult ASD is available.

The social condition associated with ASD is multifaceted with challenges in social-emotional reciprocity, social non-verbal communication, and developing, understanding, and maintaining relationships. 'Symptoms must be present in the early developmental period, but may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies later in life' (American Psychiatric Association 2013, p. 50). ASD starts when children are infants or toddlers, continues into adulthood, and thus can be seen as a lifelong condition, with an estimated prevalence rate of 2.2% for adults in the United States (Dietz et al. 2020). Although no single one of the symptoms indicates that a person meets criteria for ASD, a person who shows a number of these symptoms is a likely candidate for an ASD diagnosis and should be screened and assessed appropriately. ASD is usually diagnosed early in life, but ASD is being increasingly recognized and first-time diagnosed in adults who have not been diagnosed in childhood. Four independent studies showed that the mean age of these adulthood diagnoses is between 30 and 45 years (Geurts & Jansen 2011; Happé et al. 2016; Jones et al. 2014; Lehnhardt et al. 2012). Diagnosing adults with ASD is not just a lengthy process (Rutherford et al. 2016), but is also a complex and challenging task. It becomes especially complex when issues of comorbidity and differential diagnosis arise, a high intelligence compensates for challenges, a structured support system is

available, parental and partner informants are not available, and the social disability is camouflaged (Bastiaansen et al. 2011; Huang et al. 2020; Lai & Baron-Cohen 2015). Moreover, many non-specialist healthcare professionals lack knowledge and clinical assessment skills in adult ASD (Brugha et al. 2011). Expertise in a variety of disciplines, like psychology and psychiatry, and clinicians specialized in ASD are needed to avoid misdiagnosing in ASD, as illustrated in a case series by Van Schalkwyk et al. (2015). The combination of clinical assessment skills, expertise with standardized testing, and awareness of ASD in adults is required for a valid ASD diagnosis (Wigham et al. 2019).

There is insufficient evidence for any specific formal assessment tool for ASD in adults. The best predictor of valid and reliable ASD diagnoses in children is the clinical judgment by experienced clinicians accompanied by standardized diagnostic instruments (Lord et al. 2006; Wiggins et al. 2015). For valid and reliable ASD diagnoses in adults we expect this diagnostic process to be the same. In a survey of 116 practitioners from child and adult services, 75% reported standardised instruments to be very or quite helpful for the assessment of ASD (Rogers et al. 2015). The *NICE guideline on recognition, referral, diagnosis, and management of adults on the autism spectrum* (NCCMH 2012) recommends the combined use of the *Autism Diagnostic Interview – Revised* (ADI-R; Lord et al. 1997) as a semi-structured assessment of developmental history and the *Autism Diagnostic Observation Schedule – Generic* (ADOS-G; Lord et al. 2000) as a standardised observational measure, as best practice in the diagnosis of ASD in adults. The *Dutch guideline on diagnosis and treatment of adults on the autism spectrum* (Kan et al. 2013) does not recommend a specific instrument, concluding for instance ADOS-G being inadequate for those who are intelligent and, for example, are able to camouflage the social difficulties in specific circumstances (Bastiaansen et al. 2011; Lai et al. 2011; Langmann et al. 2017; Lord et al. 2000), and ADI-R being not practical due to, among others, time consuming administering. The Dutch guideline (Kan et al. 2013) advises after identification of the need for ASD assessment in-person interviews, interaction with the adult, and an interview with the adult's childhood caregiver or someone who knew the adult very well in childhood when available. Thereby, a clinical ASD diagnosis is defined by describing core characteristics in terms of DSM (or equivalent) criteria. Thus a (semi-)structured DSM-5 interview for ASD might be helpful for quantifying ASD characteristics and the level of severity. The *Dutch Interview for Diagnostic assessment ASD in adults* (NIDA; *Nederlands Interview ten behoeve van Diagnostiek Autismspectrumstoornis bij volwassenen*) (Vuijk 2016; see Appendices 1 and 2) might be such an instrument. The development of the NIDA might fill a gap in the availability of autism-specific diagnostic instruments following the complete DSM-5 decision-making rules for diagnostic classification (Evers et al. 2021).

The goal of the present study was to examine the reliability and validity of the in-person current functioning part of the NIDA by measuring its interrater agreement, and convergent, and concurrent criterion-related validity in a Dutch sample. In this first study, we examined whether the NIDA is a psychometrically sound instrument for assessing ASD in adult males without intellectual disability only. By focusing on this specific subgroup of the autism spectrum, we intended to establish whether the NIDA is promising enough to be tested more extensively in future studies. Our research questions are: (1) Does the in-person current functioning part of the NIDA have a good interrater agreement? (2) Does the in-person current functioning part of the NIDA have a good convergent validity? (3) Does the in-person current functioning part of the NIDA have a good concurrent criterion-related validity? Most of the ASD studies focusing on the psychometric properties of assessment tools only include general population comparison groups (COM). We compared our ASD group not only with a COM group but also with a clinical group. In this way, we examined the suitability of the NIDA for clinical use and especially differentiation to conditions for which the differential diagnosis is considered to be clinical challenging. We, therefore, chose to compare the ASD group with a group of males with a clinical diagnosis of a personality disorder (PD), because several studies reporting ASD significantly associating and overlapping with some of the major PDs (Anckarsäter et al. 2006; Hofvander et al. 2009; Lai & Baron-Cohen 2015; Lugnegård et al. 2012; Vuijk et al. 2018).

2.2 Methods

2.2.1 Setting

Sarr Autism Rotterdam, Parnassia Psychiatric Institute, the Netherlands, is specialized in psychodiagnostic assessments and interventions for children, adolescents and adults with ASD. Parnassia Psychiatric Institute is a multi-site mental health institute specialized in psychodiagnostic assessments and interventions for children, adolescents, and adults with a broad range of psychiatric disorders including PD.

2.2.2 Participants

Participants have been sampled from three sources: (1) male (ex-)clients with ASD from the Sarr Autism Rotterdam; (2) male clients with PD without ASD from Parnassia Psychiatric Institute, Rotterdam, and (3) male individuals recruited from the general population by advertisements and flyers.

Inclusion criteria for the ASD group were: (1) a primary clinical diagnosis of DSM-IV AD or AS, and/or DSM-5 ASD, (2) with or without a comorbid DSM-IV/5 PD, (3) male sex, (4) age \geq 18 years, and (5) no intellectual disability, at least a completed primary school and secondary education, and (6) being able to state and/or recognize own (psychological and problematic) functioning. We have solely included males to limit heterogeneity affected by sex differences in phenotypic presentation between males and females with ASD (Loomes et al. 2017; Wilson et al. 2016). The diagnosis ASD (including AD and AS) was verified by studying the diagnostic report including the diagnosis ASD based on clinical evaluation of autism-specific behaviors by direct observation of the individual and report of developmental and behavioral history and current functioning obtained by partner, parent or mentor. The ASD had to be diagnosed in a multidisciplinary team consisting of at least a registered psychologist or psychiatrist. The multidisciplinary ASD diagnosis was blinded from the NIDA and ADOS results throughout the process. We used the SCID-5-SPQ (First et al. 2016; Dutch version: Arntz et al. 2017), a self-report screening tool, as a check for PD, which was not an inclusion criterion when scoring positive nor an exclusion criterion when scoring negative. We used the SCID-5-SPQ information to accurately map possible PDs with the SCID-5-PD (First et al. 2016; Dutch version: Arntz et al. 2017) in the ASD participants. All ASD participants were included in the analyses independent whether or not they had a comorbid PD.

Inclusion criteria for the PD group were: (1) a primary diagnosis of DSM-IV and/or DSM-5 PD, assessed with the Dutch version of the SCID-II (First et al. 1997; Dutch version: Weertman et al. 2000), SCID-5-PD, or psychological-psychiatric assessment, (2) no past or current suspicion by health care professionals of and no diagnosis of DSM-IV/DSM-5 ASD, (3) male sex, (4) age \geq 18 years, (5) no intellectual disability, at least a completed primary school and secondary education, and (6) being able to state and/or recognize own (psychological and problematic) functioning. We used the SCID-5-SPQ as a check for PD. When having five or more positive scores on this screening tool, the participant was included in this study, implicating that PD otherwise specified was included.

Inclusion criteria for the general population comparison group (COM) were: (1) no ASD and no PD diagnosis, (2) no suspicion of ASD and PD, (3) male sex, (4) age \geq 18 years, (5) no intellectual disability, at least a completed primary school and secondary education, and (6) having a reasonable degree of insight into and recognition of their (psychological) functioning. We used the SCID-5-SPQ as a check for PD. The participant was excluded from this study when having five or more positive scores on this screening tool.

Exclusion criteria for all participants were: (1) intellectual disability (IQ < 80), (2) female sex, (3) presence of current suicidal ideation, and (4) those who have received an ASD diagnosis in the past for which the NIDA was used.

Participants with ASD, participants with PD without ASD, and COM participants have been matched for age within a five-years range and education on group level.

2.2.3 Sample size estimation

For the interrater agreement, we used Krippendorff's alpha (Hayes & Krippendorff 2007), 'a conservative agreement estimate for judgments made by any number of raters, and adaptable to any level of measurement' (Van Krugten et al. 2019, p. 4; see also Lombard et al. 2002). In addition to Krippendorff's alpha values we also used Cohen's kappa (Cohen 1960) to allow comparison of interrater agreement across studies in future studies/meta-analyses. For Cohen's kappa the sample size calculation was identical to the calculation of convergent validity (see next), because the same statistic was calculated. Guidelines by Fleiss (1981) characterize kappa over 0.75 as excellent, 0.40 to 0.75 as fair to good, and below 0.40 as poor.

For the sample size calculation of convergent validity Sim and Wright (2005) indicate that with the null-hypothesis value of kappa of 0.40 (the lowest value of kappa representing clinically acceptable agreement according to Landis and Koch 1977), with 80% power and a positive value rate around .30, the sample size should be around 85 participants to detect kappa of 0.70.

Sample size calculations for concurrent criterion-related validity were performed using G*Power 3.0.10 (Faul et al. 2007). For comparisons on the total score of the NIDA of the ASD group with both the PD without ASD group and the COM group using one-way multivariate analysis of variance (MANOVA) with a power of .80, an alpha level of .05, and an expected large effect size ($=$.80) the sample size for each of the three groups needed to be minimally 24 participants.

To prevent the interrater agreement, convergent, and concurrent criterion-related validity from being underpowered, we included 30 participants in each of the three groups, thus leading to a total of 90 participants.

2.2.4 Measures

Demographic characteristics like age, marital status, and education were extracted from a questionnaire for demographic characteristics. To assess and differentiate psychological symptoms and mental disorders most commonly seen in clinical practice, like depressive disorder and social anxiety disorder, the *Standardized Assessment for Mental disorders – a semi-structured Dutch interview* (SAM; Hoogduin 1999) was administered. The SAM consists of 18 main questions and several subquestions per question. The SAM generally takes 15 to 60 minutes to administer. To date, psychometric properties of this interview have not been studied.

Primary measure

The NIDA (Vuijk 2016) is a semi-structured interview for adults and their informants (e.g., partners, family members/parents, and mentors) when ASD is a possible diagnosis for the adult individual. The primary purpose of the NIDA is to provide the DSM-5 ASD classification. The NIDA is based on DSM-5 diagnostic criteria for ASD, and follows the DSM-5 algorithm for scoring and diagnostic classification. The original Dutch NIDA as well the English version under construction are presented in Appendices 1 and 2. The NIDA includes eight questions for past and current functioning with DSM-5 based and practice-based examples that operationalize four of the five DSM-5 ASD criteria ('persistent impairments in social communication and social interaction; restricted, repetitive patterns of behavior, interests, or activities; symptoms must be present in the early developmental period and current functioning; symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning') (American Psychiatric Association 2013, p. 50). For an overview of the questions see Table 2.2A. The questions and the scoring system are presented in Table 2.5. An example is: Do you think that you are impaired in making contact with others and in sharing thoughts and feelings? Two examples of possible answers are: 1) unable to start, respond to, or keep social interactions going, and 2) only responding from one's own point of view or experience. This question is related to the social communication domain of the dyad of ASD domains as formulated in the DSM-5. For each interviewee each question is scored as 'yes' (the question is confirmed), 'questionable' (the given answer is dubious), or 'no' (the question is not confirmed) for both past and current functioning. In case several informants are interviewed about one person, the interviewer considers the scores of all interviewees per question in order to determine an overall summarized scoring ('yes', 'questionable', or 'no') per question. When there is only one interviewee, the interviewer only considers the information of this interviewee for an overall summarized score per question. For this study's purposes we rated 'no' with zero, 'questionable' with one, and 'yes' with two points. In order to obtain a DSM-5 ASD diagnosis, one has to score three times 'yes' (in our study three times two points) on questions one to three (DSM-5 ASD criterion A), two or more scores of 'yes' (in our study two or more scores of two points) on questions four to seven (DSM-5 ASD criterion B) for past or current functioning, and a 'yes' score (in our study two points) on question eight (DSM-5 ASD criterion D) for current functioning following DSM-5 ASD criteria. The NIDA generally takes 30 to 45 minutes to administer per person. For this study we use the overall summarized scores of the eight questions for current functioning, and we do not use the past scores as past functioning was not assessed in this first study, comparing NIDA with ADOS-2 (Lord et al. 2012), the latter exclusively focusing on current functioning and in-person assessment.

Secondary measures

The *Autism Diagnostic Observation Schedule – Second edition* (ADOS-2; Lord et al. 2012; Dutch version: De Bildt et al. 2013), the updated version of ADOS-G (Lord et al. 2000), is a standardised observational measure for assessing ASD. The ADOS-2 generally takes 30 to 60 minutes to administer in which a series of opportunities are provided for the participant to show social and communication behaviors relevant to the ASD diagnosis. The ADOS-2 module 4, consisting of 32 items, is the only instrument for assessing ASD in adults that has been validated with good predictive value for ASD. The ADOS-2 shows fair interrater agreement in naturalistic clinical settings (Zander et al. 2016). A sum score of eight or more points (for clinical practice) and 10 or more points (for more specificity in academic research) on 15 items is indicative for ASD (De Bildt et al. 2016; Hus & Lord 2014). For this study we use the revised algorithm by Hus and Lord (2014).

The *Structured Clinical Interview for DSM-5 Personality Disorders* (SCID-5-PD; First et al. 2016), the updated version of the former *Structured Clinical Interview for Axis-II Personality Disorders* (SCID-II; First et al. 1997), is a semi-structured clinical interview for assessing the ten DSM-5 PDs in 106 questions. The SCID generally takes 60 to 120 minutes to administer. The SCID-5-PD incorporates the SCID-5-SPQ, a brief 20-minutes self-report screening tool with 106 questions corresponding directly to each first question in the full SCID-5-PD. The Italian translation of SCID-5-PD shows adequate interrater agreement (Somma et al. 2017). To date, further psychometric properties of SCID-5-PD are unknown. For this study we use the scores on the 106 SCID-5-PD questions after first being screened on PD with the SCID-5-SPQ.

2.2.5 Procedure

To decide if a person could participate in one of the three groups, and for general information, the SCID-5-SPQ and a questionnaire for general information about primary diagnosis, age, education, marital status, etc., were administered. When eligible for one of the three groups according to this first assessment, each participant was once interviewed by a psychologist, and once interviewed and observed by two other psychologists. The NIDA, ADOS-2, SCID-5-PD interview, and SAM were administered to all participants ($N = 90$). All interviewers and observers were well trained and educated in ASD in adults, and in each of the aforementioned assessment tools. The interviewers and observers were blind for diagnostic group, and were not permitted to obtain other sources of information to ensure that the final DSM-classification ASD for current functioning was based only on the results of the NIDA.

To establish the interrater agreement of the NIDA, we studied the outcomes on the items of the NIDA between the interviewer and the observer, independently judging the item scores for current functioning on this instrument. Two psychologists jointly

assessed 90 participants (30 with ASD, 30 with PD without ASD, and 30 COM). Both present during the assessment one performed the interview, the second observed, and both have independently evaluated the participant according to this instrument.

Convergent validity (sensitivity and specificity) was established in three ways. First, the 'yes' or 'no' current ASD scores on the NIDA and the ADOS-2 clinical cut off and scientific cut off scores were compared for the three groups. Second, we compared the 'yes' or 'no' current ASD scores on the NIDA to the clinically assessed DSM-IV or DSM-5 ASD diagnosis ('yes' for current ASD). Third, we compared the 'yes' or 'no' current ASD scores on the NIDA or the ADOS-2 as well as on the NIDA and the ADOS-2, both compared to the clinically assessed DSM-IV or DSM-5 ASD diagnosis ('yes' for current ASD). The order of the NIDA and ADOS-2 was counterbalanced across participants. The NIDA and ADOS-2 were administered by the same psychologists' duo: one interviewed and the second observed or vice versa.

To establish concurrent criterion-related validity, we compared the scores on the NIDA between three groups of participants, expecting the ASD group to score higher than the other two groups. The psychologist assessing DSM-5 disorders with the SAM assessed PDs with the SCID-5-PD interview in all three groups.

2.2.6 Statistical analysis

Statistical analyses were performed using SPSS (Statistical Package for the Social Sciences) version 25 (IBM SPSS Version 25, IBM, New York, NY, USA). Demographic characteristics were examined using descriptive statistics (means, SD, ranges, percentages).

To examine interrater agreement, Krippendorff's alpha values (Hayes & Krippendorff 2007) and Cohen's kappa values were calculated for each of the eight items for current functioning of the NIDA (i.e. DSM-5 ASD criteria A, B and D), as well as for the diagnostic conclusion ('yes' or 'no' current ASD) based on the NIDA, comparing the two raters. For each of the estimated Krippendorff's alpha values, 95% confidence intervals (CIs) were computed based on 10,000 bootstrap replications, with a minimum recommended agreement level of 0.667 (Krippendorff 2012). We regarded a Cohen's kappa of 0.70 as an indication of a good interrater agreement.

To examine convergent validity of ASD assessment, we calculated Cohen's kappa in three ways: (1) NIDA and ADOS-2 converged if they both resulted in 'yes' or 'no' current ASD, (2) NIDA converged with a clinical diagnosis of ASD if NIDA resulted in 'yes' current ASD, and (3) we compared the NIDA or the ADOS-2 as well as the NIDA and the ADOS-2, both compared to the clinically assessed DSM-IV or DSM-5 ASD diagnosis ('yes' for current ASD). We regarded a Cohen's kappa of 0.70 as an indication of a good convergent validity.

To examine concurrent criterion-related validity, one-way MANOVA followed up by Bonferroni corrected pairwise comparisons between groups was used to determine whether there were statistically significant differences in NIDA and ADOS-2 item scores.

2.3 Results

2.3.1 Demographic characteristics

A total of 90 male participants were included (30 per group). Mean age was comparable for the three groups (ASD, PD, and COM). After the SCID-5-PD assessment seven formerly diagnosed PD participants no longer met the criteria for a (specified) PD. Based on the detailed information provided in their client charts, we decided to still include these participants in the PD group given their general and long-term patterns of personality pathology. Table 2.1 gives an overview of the demographic characteristics of all participants.

Table 2.1 Demographic characteristics of participants ($N = 90$)

		ASD	PD	COM
<i>n</i>		30	30	30
Age, years	Mean	43.23	44.13	44.37
	SD	11.00	12.64	14.85
	Range	18-62	19-63	18-65
Marital status	Unmarried	23 (77%)	19 (63%)	18 (60%)
	Married	7 (23%)	4 (13%)	9 (30%)
	Divorced	0	6 (20%)	0
	Other	0	1 (3%)	3 (10%)
Education	University	7 (23%)	3 (10%)	10 (33%)
	Higher vocational education	8 (27%)	10 (33%)	13 (43%)
	Secondary school	8 (27%)	8 (27%)	6 (20%)
	Lower vocational education	5 (17%)	6 (20%)	0
	Elementary school	1 (3%)	2 (7%)	0
	Unknown/other	1 (3%)	1 (3%)	1 (3%)
ASD diagnosis [†]		30	0	0
	Autistic disorder	6 (20%)		
	Asperger's disorder	10 (33%)		
	Autism spectrum disorder	14 (47%)		

Table 2.1 Continued

	ASD	PD	COM
PD diagnosis [‡]	n=18	n=30 [§]	n=23 [¶]
Avoidant PD	1 (3%)	3 (10%)	7 (23%)
Dependent PD	0	1 (3%)	1 (3%)
Obsessive-compulsive PD	5 (18%)	0	4 (13%)
Paranoid PD	0	0	0
Schizotypal PD	0	0	0
Schizoid PD	3 (10%)	0	0
Histrionic PD	0	0	0
Narcissistic PD	0	3 (10%)	2 (7%)
Borderline PD	0	7 (23%)	5 (17%)
Antisocial PD	1 (3%)	1 (3%)	3 (10%)
Other specified PD (≥5 traits)	12 (40%)	19 (63%)	15 (50%)
Psychological symptoms and disorders [‡]			
Alcohol, drugs, and medication problems	2 (7%)	4 (13%)	
Psychotic symptoms	1 (3%)	0 (0%)	
Depressive disorder	5 (17%)	11 (37%)	
Panic disorder	2 (7%)	2 (7%)	
PTSD	3 (10%)	4 (13%)	
Specific phobia	1 (3%)	1 (3%)	
Social anxiety disorder	1 (3%)	6 (20%)	
Generalized anxiety disorder	1 (3%)	3 (10%)	
Obsessive-compulsive disorder	2 (7%)	2 (7%)	
Somatic symptom disorder and related disorders	0 (0%)	2 (7%)	
Eating disorders	0 (0%)	1 (3%)	
Adjustment disorder	2 (7%)	1 (3%)	
Relational problems	1 (3%)	2 (7%)	
Bereavement disorder	1 (3%)	1 (3%)	
Problems with aggression	1 (3%)	2 (7%)	
Other complaints	3 (10%)	2 (7%)	

ASD = Autism spectrum disorder; COM = General population comparison group; PD = Personality disorder; PTSD = Posttraumatic stress disorder.

[†] ASD diagnosis was a clinically assessed diagnosis without using NIDA.

[‡] The number of participants assessed with PD diagnosis is lower than the total number of specific PDs. The explanation for this difference is that some participants have been assessed with more than one specific PD.

[§] PDs assessed in the past with the Dutch version of the SCID-II, SCID-5-PD, or psychological-psychiatric assessment.

[¶] PDs assessed with SCID-5-PD in current NIDA study.

[‡] Psychological symptoms and disorders were assessed with a semi-structured interview for mental disorders in this study.

2.3.2 Research question 1: Interrater agreement

The interrater agreement of the in-person current functioning part of the NIDA items ranged from .80 to .95 (Krippendorff's alpha values). See Table 2.2A for details for the findings regarding each question of the NIDA. For the agreement on the diagnostic conclusion ('yes' or 'no' current ASD) based on the in-person current functioning of the NIDA Krippendorff's alpha value was 1.00. There was 100% agreement as both raters agreed on the ASD diagnosis for 25 out of the 30 ASD participants, on no ASD diagnosis for 5 out of 30 ASD participants, and on no ASD diagnosis for all PD and COM participants.

In addition to Krippendorff's alpha values, we also reported Cohen's kappa values to allow comparison of interrater agreement across studies in future studies/meta-analyses presented in Table 2.2B.

Table 2.2A Interrater reliability of the NIDA

	Krippendorff's alpha	CI
NIDA questions		
1. Do you think that you are impaired in making contact with others and in sharing thoughts and feelings?	.95	(0.88-1.00)
2. Do you think that you are impaired in your non-spoken way of communicating?	.93	(0.83-1.00)
3. Do you think that you are impaired in starting, maintaining, and understanding relationships?	.91	(0.81-0.98)
4. Do you have a typical or repetitive way of moving, of using objects, or of speaking?	.83	(0.65-0.97)
5. Are you insistent on sameness; Do you have rigid (inflexible) routines or ritualised patterns in your manner of speaking or behaving?	.80	(0.66-0.91)
6. Do you have highly restricted, fixated interests which are extreme in intensity or focus?	.84	(0.71-0.95)
7. Are you hyper- or hypo reactive to sensory input, or do you have an unusual interest in sensory aspects of the environment?	.87	(0.75-0.97)
8. In which areas do you experience distress, or do you think you are impaired in your ability to function due to the aforementioned symptoms?	.95	(0.88-1.00)
NIDA diagnostic conclusion ('yes' or 'no' current ASD)	1.00	(1.00-1.00)

CI = Confidence interval; NIDA = Dutch Interview for Diagnostic assessment of Autism spectrum disorder in Adults. Krippendorff's alpha values of the NIDA (N = 90, 95% CIs generated by two raters).

Please note that as the NIDA follows the DSM-5 criteria closely, only the often considered negative aspects of ASD have been included.

Table 2.2B Interrater reliability of the NIDA

	Cohen's kappa	CI	SE
NIDA questions			
1. Do you think that you are impaired in making contact with others and in sharing thoughts and feelings?	.95	(0.88-1.01)	0.034
2. Do you think that you are impaired in your non-spoken way of communicating?	.93	(0.84-1.00)	0.041
3. Do you think that you are impaired in starting, maintaining, and understanding relationships?	.90	(0.81-0.99)	0.045
4. Do you have a typical or repetitive way of moving, of using objects, or of speaking?	.83	(0.69-0.97)	0.072
5. Are you insistent on sameness; Do you have rigid (inflexible) routines or ritualised patterns in your manner of speaking or behaving?	.79	(0.67-0.91)	0.061
6. Do you have highly restricted, fixated interests which are extreme in intensity or focus?	.87	(0.75-0.97)	0.057
7. Are you hyper- or hypo reactive to sensory input, or do you have an unusual interest in sensory aspects of the environment?	.87	(0.76-0.97)	0.053
8. In which areas do you experience distress, or do you think you are impaired in your ability to function due to the aforementioned symptoms?	.95	(0.88-1.01)	0.033

CI = Confidence interval; NIDA = Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults; SE = Standard error.
Cohen's kappa values of the NIDA (N = 90, 95% CIs generated by two raters).
Please note that as the NIDA follows the DSM-5 criteria closely, only the often considered negative aspects of ASD have been included.

Table 2.3 Sensitivity and specificity of NIDA and ADOS-2

	Sen	Spec	Cohen's kappa	CI	SE
Current study:					
NIDA based on ADOS-2 cut-off 8	.76	1.00	.80	(0.67 - 0.93)	0.07
NIDA based on ADOS-2 cut-off 10	.89	.98	.89	(0.79 - 1.00)	0.05
NIDA based on clinical diagnosis ASD	.83	1.00	.87	(0.76 - 0.98)	0.06
ADOS-2 cut-off 8 based on clinical diagnosis ASD	.96	.93	.88	(0.77 - 0.98)	0.05
ADOS-2 cut-off 10 based on clinical diagnosis ASD	.90	1.00	.92	(0.84 - 1.00)	0.04
NIDA or ADOS-2 cut-off 8 based on clinical diagnosis ASD	.96	.93	.88	(0.77 - 0.98)	0.05
NIDA or ADOS-2 cut-off 10 based on clinical diagnosis ASD	.93	1.00	.95	(0.88 - 1.00)	1.00
NIDA and ADOS-2 cut-off 8 based on clinical diagnosis ASD	.83	1.00	.87	(0.76 - 0.98)	0.06
NIDA and ADOS-2 cut-off 10 based on clinical diagnosis ASD	.90	1.00	.92	(0.84 - 1.00)	0.04
Previous study findings:					
ADOS-2 cut-off 8 (Hus & Lord, 2014)	.92	.77			
ADOS-2 cut-off 8 (Pugliese et al., 2015)	.83	.65			
ADOS-2 cut-off 8 (De Bildt et al., 2016)	.61	1.00			
ADOS-2 cut-off 10 (De Bildt et al., 2016)	.53	1.00			
ADOS-2 cut-off 8 (Fusar-Poli et al., 2015)	.87	.74			
ADOS-2 cut-off 7 (Langmann et al., 2017)	.82	.83			
ADOS-2 cut-off 10 (Langmann et al., 2017)	.57	.92			

ADOS-2 = Autism Diagnostic Observation Schedule; ASD = Autism spectrum disorder; CI = Confidence interval; NIDA = Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults; SE = Standard error; Sen = Sensitivity; Spec = Specificity.

2.3.3 Research question 2: Convergent validity

The convergent validity of the in-person current functioning part of the NIDA with both ADOS-2 cut offs and with the clinical diagnosis ranged from .80 to .95 (Cohen's kappa). The sensitivity of the NIDA items ranged from .76 to .96, and the specificity from .93 to 1.00. See Table 2.3 for details of the findings regarding each of the different measures as well for the comparison of our ADOS-2 sensitivity and specificity with the findings reported in previous studies evaluating ADOS-2 module 4.

2.3.4 Research question 3: Concurrent criterion-related validity

The MANOVA on the items of the in-person current functioning part of the NIDA revealed a statistically significant effect of group, $F(18,158) = 47.73, p < .001$; Wilk's $\Lambda = 0.024, \eta_p^2 = .85$. The MANOVA on the items of the ADOS-2 Module 4 revealed a statistically significant effect of group, $F(30, 146) = 9.39, p < .001$; Wilk's $\Lambda = 0.116, \eta_p^2 = .66$. Bonferroni corrected pairwise comparisons (presented in Table 2.4) revealed that the differences between the ASD and the PD group as well the ASD and COM group were significant. The difference between the PD and COM group was non-significant. The multivariate effect size of the NIDA ($\eta_p^2 = .85$) was larger than that of the ADOS-2 ($\eta_p^2 = .66$). Distribution of scores on all NIDA items and ADOS-2 Module 4 algorithm items for all participants are presented in Table 2.5.

Table 2.4 Pairwise comparisons of NIDA and ADOS-2 item and total scores

	<i>n</i>	Mean	SD	SE	Comparison	Mean difference	SE	CI	df	<i>p</i>
NIDA										
Item 1										
ASD	30	2.0	0	.04	ASD-PD	1.93	.05	(1.80 - 2.07)	2	<.001
PD	30	0.07	0.37	.04	ASD-COM	2.00	.05	(1.87 - 2.13)	2	<.001
COM	30	0	0	.04	PD-COM	0.07	.05	(-0.07 - 0.20)	2	0.672
Item 2										
ASD	30	1.93	0.37	.06	ASD-PD	1.83	.08	(1.74 - 2.03)	2	<.001
PD	30	0.10	0.40	.06	ASD-COM	1.93	.08	(1.74 - 2.13)	2	<.001
COM	30	0	0	.06	PD-COM	0.10	.08	(-0.10 - 0.30)	2	0.661
Item 3										
ASD	30	1.83	0.53	.07	ASD-PD	1.73	.10	(1.49 - 1.98)	2	<.001
PD	30	0.10	0.40	.07	ASD-COM	1.83	.10	(1.59 - 2.08)	2	<.001
COM	30	0	0	.07	PD-COM	0.10	.10	(-0.14 - 0.34)	2	0.950
Item 4										
ASD	30	1.17	0.99	.11	ASD-PD	1.13	.15	(0.77 - 1.50)	2	<.001
PD	30	0.03	0.18	.11	ASD-COM	1.17	.15	(0.80 - 1.53)	2	<.001
COM	30	0	0	.11	PD-COM	0.03	.15	(-0.33 - 0.40)	2	1.000
Item 5										
ASD	30	1.67	0.71	.10	ASD-PD	1.40	.14	(1.05 - 1.75)	2	<.001
PD	30	0.27	0.64	.10	ASD-COM	1.67	.14	(1.32 - 2.01)	2	<.001
COM	30	0	0	.10	PD-COM	0.27	.14	(-0.08 - 0.61)	2	0.194
Item 6										
ASD	30	1.60	0.81	.11	ASD-PD	1.37	.15	(0.99 - 1.74)	2	<.001
PD	30	0.23	0.63	.11	ASD-COM	1.60	.15	(1.23 - 1.97)	2	<.001
COM	30	0	0	.11	PD-COM	0.23	.15	(-0.14 - 0.61)	2	0.393
Item 7										
ASD	30	1.40	0.89	.12	ASD-PD	1.07	.18	(0.64 - 1.49)	2	<.001
PD	30	0.33	0.76	.12	ASD-COM	1.40	.18	(0.97 - 1.83)	2	<.001
COM	30	0	0	.12	PD-COM	0.33	.18	(-0.09 - 0.76)	2	0.179
Item 8										
ASD	30	2	0	.64	ASD-PD	1.80	.09	(1.58 - 2.02)	2	<.001
PD	30	0.20	0.61	.64	ASD-COM	2.00	.09	(1.78 - 2.22)	2	<.001
COM	30	0	0	.64	PD-COM	0.20	.09	(-0.02 - 0.42)	2	0.092

Table 2.4 Continued

	<i>n</i>	Mean	SD	SE	Comparison	Mean difference	SE	CI	df	<i>p</i>
ADOS-2										
Item A2										
ASD	30	1.17	0.65	.09	ASD-PD	0.93	.13	(0.61 - 1.25)	2	<.001
PD	30	0.23	0.50	.09	ASD-COM	1.07	.13	(0.75 - 1.39)	2	<.001
COM	30	0.10	0.31	.09	PD-COM	0.13	.13	(-0.19 - 0.45)	2	0.930
Item A4										
ASD	30	0.63	0.62	.83	ASD-PD	0.37	.12	(0.08 - 0.65)	2	0.007
PD	30	0.27	0.45	.83	ASD-COM	0.60	.12	(0.31 - 0.89)	2	<.001
COM	30	0.03	0.18	.83	PD-COM	0.23	.12	(-0.05 - 0.52)	2	0.147
Item A8										
ASD	30	0.80	0.76	.10	ASD-PD	0.60	.13	(0.27 - 0.93)	2	<.001
PD	30	0.20	0.41	.10	ASD-COM	0.73	.13	(0.41 - 1.06)	2	<.001
COM	30	0.07	0.25	.10	PD-COM	0.13	.13	(-0.19 - 0.46)	2	0.969
Item A10										
ASD	30	1.13	0.78	.11	ASD-PD	0.90	.16	(0.51 - 1.29)	2	<.001
PD	30	0.23	0.63	.11	ASD-COM	1.03	.16	(0.64 - 1.42)	2	<.001
COM	30	0.10	0.40	.11	PD-COM	0.13	.16	(-0.26 - 0.52)	2	1.000
Item B1										
ASD	30	1.67	0.76	.10	ASD-PD	1.53	.14	(1.20 - 1.87)	2	<.001
PD	30	0.13	0.51	.10	ASD-COM	1.67	.14	(1.33 - 2.00)	2	<.001
COM	30	0	0	.10	PD-COM	0.13	.14	(-0.20 - 0.47)	2	0.989
Item B2										
ASD	30	1.03	0.32	.08	ASD-PD	0.67	.11	(0.41 - 0.93)	2	<.001
PD	30	0.37	0.56	.08	ASD-COM	0.93	.11	(0.67 - 1.19)	2	<.001
COM	30	0.10	0.31	.08	PD-COM	0.27	.11	(0.01 - 0.53)	2	0.041
Item B5										
ASD	30	1.13	0.63	.09	ASD-PD	0.73	.13	(0.41 - 1.06)	2	<.001
PD	30	0.40	0.50	.09	ASD-COM	0.97	.13	(0.64 - 1.29)	2	<.001
COM	30	0.17	0.38	.09	PD-COM	0.23	.13	(-0.09 - 0.56)	2	0.244
Item B7										
ASD	30	0.93	0.79	.09	ASD-PD	0.77	.13	(0.44 - 1.09)	2	<.001
PD	30	0.17	0.38	.09	ASD-COM	0.90	.13	(0.58 - 1.22)	2	<.001
COM	30	0.03	0.18	.09	PD-COM	0.13	.13	(-0.19 - 0.46)	2	0.954
Item B9										
ASD	30	1.07	0.64	.09	ASD-PD	0.77	.13	(0.46 - 1.08)	2	<.001
PD	30	0.27	0.47	.09	ASD-COM	0.97	.13	(0.66 - 1.28)	2	<.001
COM	30	0	0.31	.09	PD-COM	0.20	.13	(-0.11 - 0.51)	2	0.352

Table 2.4 Continued

	<i>n</i>	Mean	SD	SE	Comparison	Mean difference	SE	CI	df	<i>p</i>
Item B11										
ASD	30	0.87	0.35	.06	ASD-PD	0.60	.09	(0.39 - 0.81)	2	<.001
PD	30	0.27	0.45	.06	ASD-COM	0.87	.09	(0.66 - 1.07)	2	<.001
COM	30	0	0	.06	PD-COM	0.27	.09	(0.06 - 0.47)	2	0.007
Item B12										
ASD	30	0.90	0.61	.08	ASD-PD	0.73	.11	(0.46 - 1.00)	2	<.001
PD	30	0.17	0.38	.08	ASD-COM	0.87	.11	(0.60 - 1.14)	2	<.001
COM	30	0.03	0.18	.08	PD-COM	0.13	.11	(-0.14 - 0.40)	2	0.688
Item B13										
ASD	30	0.87	0.57	.10	ASD-PD	0.20	.13	(-0.13 - 0.53)	2	0.422
PD	30	0.67	0.61	.10	ASD-COM	0.73	.13	(0.41 - 1.06)	2	<.001
COM	30	0.13	0.35	.10	PD-COM	0.53	.13	(0.21 - 0.86)	2	<.001
Item D1										
ASD	30	0.53	0.73	.09	ASD-PD	0.47	.13	(0.14 - 0.79)	2	0.002
PD	30	0.07	0.25	.09	ASD-COM	0.40	.13	(0.08 - 0.72)	2	0.010
COM	30	0.13	0.43	.09	PD-COM	0.07	.13	(-0.39 - 0.26)	2	1.000
Item D2										
ASD	30	0.27	0.64	.07	ASD-PD	0.27	.10	(0.02 - 0.51)	2	0.026
PD	30	0	0	.07	ASD-COM	0.23	.10	(-0.01 - 0.48)	2	0.063
COM	30	0.03	0.18	.07	PD-COM	0.03	.10	(-0.28 - 0.21)	2	1.000
Item D4										
ASD	30	0.33	0.55	.07	ASD-PD	0.23	.10	(0 - 0.47)	2	0.056
PD	30	0.10	0.31	.07	ASD-COM	0.30	.10	(0.06 - 0.54)	2	0.08
COM	30	0.03	0.18	.07	PD-COM	0.07	.10	(-0.17 - 0.30)	2	1.000
NIDA total score										
ASD	30	6.70	1.15	.18	ASD-PD	6.13	.25	(5.54 - 6.72)	2	<.001
PD	30	0.57	1.19	.18	ASD-COM	6.70	.25	(6.11 - 7.29)	2	<.001
COM	30	0	0	.18	PD-COM	0.57	.25	(-0.04 - 1.17)	2	.073
ADOS-2 total score										
ASD	30	13.33	3.31	.61	ASD-PD	9.77	.67	(8.13 - 11.40)	2	<.001
PD	30	3.56	2.71	.50	ASD-COM	12.27	.67	(10.63 - 13.90)	2	<.001
COM	30	1.07	1.36	.25	PD-COM	2.50	.67	(0.86 - 4.14)	2	<.001

ADOS-2 = Autism Diagnostic Observation Schedule; ASD = Autism spectrum disorder; CI = Confidence interval (95%); COM = Comparison group of nonpatient individuals; df = Degrees of freedom; NIDA = Dutch Interview for Diagnostic assessment of ASD in adults; PD = Personality disorder; SD = Standard deviation; SE = Standard error.

2.4 Discussion

In the present cross-sectional study, we aimed to explore the utility of a new ASD assessment instrument for adults, the NIDA by determining the interrater agreement and validity of the in-person current functioning part of the interview among adult males without intellectual disability. The in-person current functioning part of the NIDA seems psychometrically sound when used in males as: a) the interrater agreement; b) the convergent validity with the ADOS-2 and the clinical diagnosis of ASD; c) the sensitivity and the specificity; and d) the concurrent criterion-related validity can all considered to be very good. The NIDA and ADOS-2 were comparable with respect to how well they discriminate between males with ASD, males with PD, and males without either ASD or PD. Using the NIDA and ADOS-2 simultaneously resulted in similar sensitivity and specificity scores as when using either one of both. The NIDA and the ADOS-2 are different instruments, an interview and an observation respectively: based on our study it seems that both instruments can be recommended for use in clinical practice.

Having demonstrated these first promising NIDA psychometric properties, we next explored whether our ADOS-2 findings are in line with previous ADOS-2 findings. We compared our ADOS-2 results with the results reported in previous studies evaluating ADOS-2 Module 4 (see Table 2.3). In these studies, ADOS-2 sensitivity estimates ranged from 53% to 92%, and ADOS-2 specificity estimates ranged from 65% to 100% (De Bildt et al. 2016; Fusar-Poli et al. 2017; Hus & Lord, 2014; Langmann et al. 2017; Pugliese et al. 2015). Our ADOS-2 specificity estimates were higher compared to most previous studies and comparable for the study of De Bildt et al. (2016). Moreover, our ADOS-2 sensitivity estimates were higher compared to most previous studies and comparable to one study (Hus & Lord, 2014; a clinical subsample of adolescents and adults [VIQ 85-115]). The largest difference in ADOS-2 sensitivity between our and another study is with the study of De Bildt et al. (2016). This study included participants with a diagnosis of PDD-NOS who might be presenting less ASD characteristics and/or less obvious ASD characteristics. These ADOS-2 findings suggest our study having clearly defined groups of participants. Hence, focusing on males without an intellectual disability seemed to have successfully reduced heterogeneity of the ASD sample as we anticipated in our study design.

Interestingly, we observed a rather clear distinction between the ASD group and the PD group on the NIDA as well as with respect to the ADOS-2 scores. This finding is in contrast with the dominant view in the literature. For example (see also Table 2.4), we observed a clear distinction regarding the means of the total scores on the NIDA between the ASD group and the PD group. While this seems unexpected, there is a clear explanation for this difference between the literature so far and our study. We explicitly only included males with overt ASD presentations and who do not seem

Table 2.5 Distribution of scores on NIDA and ADOS-2 in three diagnostic groups

Score	ASD						PD						COM					
	0	1	2	Range	Mean	SD	0	1	2	Range	Mean	SD	0	1	2	Range	Mean	SD
	n (%)	n (%)	n (%)				n (%)	n (%)	n (%)				n (%)	n (%)	n (%)			
NIDA items																		
1. Do you think that you are impaired in making contact with others and in sharing thoughts and feelings?	0	0	30 (100)	0	2.00	0.00	29 (97)	0	1 (3)	0-2	0.07	0.37	30 (100)	0	0	0	0	0
2. Do you think that you are impaired in your non spoken way of communicating?	1 (3)	0	29 (97)	0-2	1.93	0.37	28 (93)	1 (3)	1 (3)	0-2	0.10	0.40	30 (100)	0	0	0	0	0
3. Do you think that you are impaired in starting, maintaining and understanding relationships?	2 (7)	1 (3)	27 (90)	0-2	1.83	0.53	28 (93)	1 (3)	1 (3)	0-2	0.10	0.40	30 (100)	0	0	0	0	0
4. Do you have a typical or repetitive way of moving, of using objects or of speaking?	12 (40)	1 (3)	17 (57)	0-2	1.17	0.99	29 (97)	1 (3)	0	0-1	0.03	0.18	30 (100)	0	0	0	0	0
5. Are you insistent on sameness, do you have rigid (inflexible) routines or ritualised patterns in your manner of speaking or behaving?	4 (13)	2 (7)	24 (80)	0-2	1.67	0.71	25 (83)	2 (7)	3 (10)	0-2	0.27	0.64	30 (100)	0	0	0	0	0
6. Do you have highly restricted, fixated interests which are extreme in intensity or focus?	6 (20)	0	24 (80)	0-2	1.60	0.81	26 (87)	1 (3)	3 (10)	0-2	0.23	0.63	30 (100)	0	0	0	0	0
7. Are you hyper- or hypo reactive to sensory input or do you have an unusual interest in sensory aspects of the environment?	8 (27)	2 (7)	20 (67)	0-2	1.40	0.89	25 (83)	0	5 (17)	0-2	0.33	0.76	30 (100)	0	0	0	0	0
8. In which areas do you experience distress or do you think that you are impaired in your ability to function due to the aforementioned symptoms?	0	0	30 (100)	0	2.00	0.00	27 (90)	0	3 (10)	0-2	0.20	0.61	30 (100)	0	0	0	0	0
ADOS-2 items																		
A2 Speech abnormalities	4 (13)	17 (57)	9 (30)	0-2	1.17	0.65	24 (80)	5 (17)	1 (3)	0-2	0.23	0.50	27 (90)	3 (10)	0	0-1	0.10	0.31
A4 Stereotype language	13 (43)	15 (50)	2 (7)	0-2	0.63	0.62	22 (73)	8 (27)	0	0-1	0.27	0.45	29 (97)	1 (3)	0	0-1	0.03	0.18
A8 Conversation	12 (40)	12 (40)	6 (20)	0-2	0.80	0.76	24 (80)	6 (20)	0	0-1	0.20	0.41	28 (93)	2 (7)	0	0-1	0.07	0.25
A10 Empathic gestures	7 (23)	12 (40)	11 (37)	0-2	1.13	0.78	26 (87)	1 (3)	3 (10)	0-2	0.23	0.63	28 (93)	1 (3)	1 (3)	0-2	0.10	0.40
B1 Unusual eye contact†	5 (17)		25 (83)	0-2	1.67	0.76	28 (93)		2 (7)	0-2	0.13	0.51	30 (100)		0	0	0	0
B2 Facial expression	1 (3)	27 (90)	2 (7)	0-2	1.03	0.32	20 (67)	9 (30)	1 (3)	0-2	0.37	0.56	27 (90)	3 (10)	0	0-1	0.10	0.30
B5 Communication own affect	4 (13)	18 (60)	8 (27)	0-2	1.13	0.63	18 (60)	12 (40)	0	0-1	0.40	0.50	25 (83)	5 (17)	0	0-1	0.17	0.38
B7 Insight	10 (33)	12 (40)	8 (27)	0-2	0.93	0.79	25 (83)	5 (17)	0	0-1	0.17	0.38	29 (97)	1 (3)	0	0-1	0.03	0.18
B9 Quality of social overtures	5 (17)	18 (60)	7 (23)	0-2	1.07	0.64	21 (70)	9 (30)	0	0-1	0.30	0.47	27 (90)	1 (3)	0	0-1	0.10	0.30
B11 Quality of response	4 (13)	26 (87)	0	0-1	0.87	0.35	22 (73)	8 (27)	0	0-1	0.27	0.45	30 (100)	0	0	0	0	0
B12 Amount of social communication	7 (23)	19 (63)	4 (13)	0-2	0.90	0.61	25 (83)	5 (17)	0	0-1	0.17	0.38	29 (97)	1 (3)	0	0-1	0.03	0.18
B13 Quality of rapport	7 (23)	20 (67)	3 (10)	0-2	0.87	0.57	12 (40)	16 (53)	2 (7)	0-2	0.67	0.61	26 (87)	4 (13)	0	0-1	0.13	0.35
D1 Unusual sensory interest	18 (60)	8 (27)	4 (13)	0-2	0.53	0.73	28 (93)	2 (7)	0	0-1	0.07	0.25	27 (90)	2 (7)	1 (3)	0-2	0.13	0.43
D2 Hand mannerisms	25 (83)	2 (7)	3 (10)	0-2	0.27	0.64	30 (100)	0	0	0	0	0	29 (97)	1 (3)	0	0-1	0.03	0.18
D4 Highly specific topics	21 (70)	8 (27)	1 (3)	0-2	0.33	0.55	27 (90)	3 (10)	0	0-1	0.10	0.31	29 (97)	1 (3)	0	0-1	0.03	0.18

ADOS-2 = Autism Diagnostic Observation Schedule; ASD = Autism Spectrum Disorder; Com = Comparison group of nonpatient individuals; NIDA = Dutch Interview for Diagnostic assessment of ASD in adults; PD = Personality Disorder; SD = Standard Deviation.

B1 Unusual eye contact† : for this item there is only a score of zero and two points.

Scoring NIDA: 0 means the item is not confirmed, 1 means the given answer is questionable, 2 means the item is confirmed. For classifying ASD the sum score for items 1, 2, and 3 must be three times two points, the sum score for items 4,5,6, and 7 must be at least two scores of two points, and the score for item 8 must be two points.

Scoring ADOS-2: 0 means behavior of type specified is not present, 1 means behavior of type specified is present, but not sufficient severe, frequent, or marked for two points, 2 means behavior of type specified is present and meets specific mandatory criteria.

Please note that as the NIDA follows the DSM-5 criteria closely only the often considered negative aspects of ASD have been included.

to be camouflaging their social disability. Moreover, the included males with PD had absolutely no past or current suspicion on ASD. Hence this increased the likelihood of observing such a difference. Whether in a sample of participants who might all be suspected having an ASD this will be as clear as in the current study is debatable. Our selection procedure also implies that while this first study into the psychometric properties of a part of the NIDA is promising, the NIDA does need to be put further to the test with less obvious ASD samples. The low comorbidity with co-occurring conditions observed in the present samples also indicates that future studies should use samples with (at least initially) less clear diagnostic characteristics. As the males we selected for the ASD and PD group were recruited in a psychiatric institute, at the end of their treatment or already dismissed from treatment, this could well have resulted in the observed lower prevalence of co-occurring mental health conditions compared to what is to be expected from clients with ASD and/or PD when referred for diagnosis and treatment.

Next to the aforementioned limitation regarding representativeness of the overall ASD and PD population, other limitations are: the exclusive inclusion of males, the exclusion of males with an intellectual disability, the small sample sizes, the lack of more than one clinical comparison group, and the fact that PD diagnoses of the PD participants were not all based on a 'gold standard' DSM-interview like the SCID, leading to a few formerly diagnosed PD participants who did not or no longer met the criteria for a specified DSM-5 PD. Moreover, in this first study, we did not yet examine test-retest reliability, and we focused solely on the in-person current functioning part of the NIDA while for an ASD diagnosis following the DSM-5 the past functioning part of the NIDA is also of relevance.

The key strengths of this study are the broad age range of the sample, the recruitment of all participants with ASD directly from a clinical setting specialized in psychodiagnostic assessments and psychotherapeutic treatment for adults with ASD, and the comparison of three different groups including a PD group which make the results more relevant for clinical practice. Further, to our knowledge, this is the first study in which an interview based on DSM-5 ASD criteria administered to adults with ASD is validated for males.

Future research is needed to critically review and to further establish the current psychometric properties of the NIDA. This instrument should be tested in a larger study in more detail and in a more diverse population (e.g., also including females). The inclusion of adults with less overt autism features and inclusion of other clinical groups with comparable social challenges, such as social anxiety disorder and obsessive-compulsive PD (Vuijk et al. 2018), or a mixed neuropsychiatric sample (ASD with comorbid ADHD) should test the NIDA's current concurrent criterion-related validity. Moreover, the NIDA focuses solely on the negative characteristics of ASD as this is in line with the formulation of the DSM-5 criteria. However, it could

well be that the concurrent criterion-related validity and construct validity improves when positive characteristics of ASD are included as well. Please note that while the NIDA is currently only available in Dutch, an English version is under construction (presented in Appendix 2).

In conclusion, this first attempt to validate the NIDA suggests that an important part of the instrument shows preliminary indications of its psychometric usefulness in adult males without intellectual disability. Both the NIDA and the ADOS-2 show good psychometric properties, considering them to be alternatives in the set of ASD psychodiagnostic instruments. The NIDA is available free of charge, with a low-threshold training, and provides a relatively brief and user-friendly semi-structured interview in the clinical ASD assessment. The ADOS-2 is not available free of charge, with an extensive training, and a time-consuming administering in clinical practice. Overall, experience and competence of the clinician in the characteristics of ASD as well PD and their resemblance and difference in phenotype remain of primary importance when assessing adults suspicious for ASD.

Part II

Personality (pathology)



3

Temperament, character, and personality disorders in adults with autism spectrum disorder: A systematic literature review and meta-analysis

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Abstract

This chapter offers a systematic review of studies of personality and the dimensions of temperament and character, personality pathology, and personality disorders (PDs) in adults with autism spectrum disorder (ASD). Fifteen studies met the inclusion criteria for the review, from which seven studies were meta-analyzed. Results indicate that ASD is significantly and systematically associated with an introvert, rigid, passive-dependent temperament with low Novelty Seeking, high Harm Avoidance, low Reward Dependence and high Persistence, and with an immature and poorly developed character with low Self-Directedness, low Cooperativeness, and high Self-Transcendence. The review further finds a positive correlation between ASD and Neuroticism, and a negative correlation between ASD and Extraversion, Openness to Experience, Agreeableness, and Conscientiousness. It also finds a positive correlation with paranoid, schizoid, schizotypal, avoidant, and obsessive-compulsive PDs. However, the far from perfect associations indicate there is considerable variation between people with ASD in their personality and personality pathology. In order to obtain a comprehensive picture of an individual with ASD and to implement the most effective intervention plans for and therapeutic relationship with adults with ASD, temperament, character, comorbid personality pathology, and PDs should be considered.

Author contributions

All authors contributed to the study conception and design. Material preparation and data collection was performed by Richard Vuijk. Data analyses were performed by Richard Vuijk and Mathijs Deen, and checked by the rest of the authors. The first draft of the manuscript was written by Richard Vuijk, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

3.1 Introduction

There is a developing, but still small amount of literature on personality and its dimensions of temperament and character, and on personality pathology and personality disorders (PDs) in adults with autism spectrum disorder (ASD). Many researchers have independently studied these concepts in adults with ASD, but no systematic reviews on this research have been carried out. The purpose of this systematic review is to summarize the existing research on personality and personality pathology in adults with ASD, and to conduct a meta-analysis of temperament, character, and PDs in adults with ASD. Implications for future research and clinical practice are discussed.

We first define ASD, personality, temperament, character, and PDs. Personality and its dimensions of temperament and character are present in all people, including those with ASD. This might account for and could advance our understanding of the considerable heterogeneity within the ASS-phenotype resulting from multiple possible etiological factors and various clinical presentations in severity, cognitive style, and concurrent comorbid conditions (De Pauw et al. 2011; Lai & Baron-Cohen 2015; Landry & Chouinard 2016; Schriber et al. 2014; Schwartzman et al. 2016). The study of personality, temperament, character, and PDs could significantly improve our understanding of adults with ASD. A greater understanding of these concepts within this population may contribute to a comprehensive picture of people with ASD and of the potential for effective interaction, intervention, and therapeutic relationship.

3.1.1 Autism spectrum disorder

Based on the most recent update of the Diagnostic and Statistical Manual (DSM-5; American Psychological Association 2013), with its onset in childhood (but sometimes not becoming fully manifest until social demands exceed limited capacities, or being masked by learned strategies in later life) ASD is an impairing neurodevelopmental disorder with social problems as a key symptom. Persons with ASD show 'persistent deficits in social communication and social interaction, and restricted, repetitive patterns of behavior, interests, and activities' (American Psychiatric Association 2013, p. 50). The participants with ASD in the studies reviewed here were all diagnosed with the former DSM-IV pervasive developmental disorders, individually classified as Autistic Disorder (AD), Asperger's Disorder (AS), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (American Psychiatric Association 2000). All three have now been incorporated into and replaced by DSM-5 ASD.

Apart from the behavioral level, ASD is associated with cognitive limitations and deficits in social cognition and social perception (Theory of Mind), executive functions, and bottom-up and top-down (local vs. global) information processing

(central coherence) (see Hutchins et al. 2016; Lai & Baron-Cohen 2015). ASD affects approximately 0.6% to 1% of the general population (Brugha et al. 2011; Elsabbagh et al. 2012; Fombonne 2005), and can be seen as a lifelong disorder causing significant lifetime disabilities (Shattuck et al. 2007). Both clinical practice and epidemiological research show that more than 70% of individuals with ASD have concurrent medical, developmental, or psychiatric conditions (like PDs) (Buck et al. 2014; Croen et al. 2015; Hofvander et al. 2009; Lai & Baron-Cohen 2015; Lugnegård et al. 2011; Mannion & Leader 2013; Supekar et al. 2017; Tebartz Van Elst et al. 2013). Above all, ASD is still associated with ‘a poorly detectable pathophysiology and an unclear etiology, course, prognosis, and treatment’ (Verhoeff 2015, p. 206; see also Waterhouse et al. 2016).

3.1.2 Personality

There are several ways to define personality. Millon (1981, p. 8) defines personality as ‘a complex pattern of deeply embedded psychological characteristics that are largely unconscious, cannot be eradicated easily, and express themselves automatically in almost every facet of functioning’. Intrinsic and pervasive, these traits emerge from a complicated matrix of biological dispositions and experiential learnings, and now comprise the individual’s distinctive pattern of perceiving, feeling, thinking, and coping. Costa and McCrae (1990, p. 23) define personality traits as ‘dimensions of individual differences in tendencies to show consistent patterns of thoughts, feelings, and actions’. Their Five-Factor Model of personality consists of Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness (Costa & McCrae 1990). Cloninger et al. (1993) developed a psychobiological model of the structure and development of personality, conceptualized as the combination of and interaction between temperament and character as the two major domains of personality, whereby temperament is close to biological substrates, and character is influenced by social-cultural factors (Strelau 2001). Any of the combinations may be found in well-functioning as well as in personality disordered individuals (Svarkic et al. 1993). When there is a problematic innate temperament and/or a problematic development of character, this may develop into a PD.

3.1.3 Temperament

Temperament refers to those aspects of an individual’s personality that are often regarded as the result of biological evolution, initially constitutionally based rather than learned (Strelau 1983). Temperament can be described as a combination of a certain level of activity, a tolerance for feelings, a certain degree of vitality, and a certain degree of extraversion/introversion, based on biological processes. The individual has a temperament from the moment he is born. The baby shapes his social environment with his temperament, and this temperament is conversely influenced by the environment. Research indicates that it is a misunderstanding

to assume that temperament is insensitive to changes over time; it has been found to be as changeable as personality traits (Roberts & DelVecchio 2000; Roberts et al. 2007). Many classification schemes for temperament have been developed, but there is still no general consensus. In this review, we will define temperament on the basis of the *Temperament and Character Inventory* (TCI; Cloninger et al. 1994), which is based on Cloninger’s ‘psychobiological theory’ of personality (Cloninger et al. 1993). The temperament scales of the TCI include the following: Novelty Seeking (exploratory excitability, impulsiveness, extravagance, disorderliness), Harm Avoidance (anticipatory worry, fear of uncertainty, shyness, fatigability, asthenia), Reward Dependence (sentimentality, attachment, dependence), and Persistence. The complex interaction between temperament and social environment influences the formation of what is called ‘character’. Certain temperament profiles can complicate a healthy character development, contributing to the development of PDs in adulthood (Anckarsäter et al. 2006).

3.1.4 Character

There are also several ways to define character. In contrast to temperament, character is theorized as less heritable, later developing, influenced by processes of maturation, and representing individual differences in self-object relationships (Cloninger et al. 1998). Allport (1937, p. 52) stated that ‘character is personality evaluated’. A healthy character is described by Cloninger et al. (1993) and Svarkic et al. (1993) as a maturity of personality in relation to self (self-directedness), to others (cooperativeness) and to a unique wholeness (self-transcendence). Character on the basis of the TCI (Cloninger et al. 1994) includes the following: Self-Directedness (responsibility, purposefulness, resourcefulness, self-acceptance, congruent second nature), Cooperativeness (social acceptance, empathy, helpfulness, compassion, pure-hearted), and Self-Transcendence (self-forgetful, transpersonal identification, spiritual acceptance).

3.1.5 Personality disorder

Personality disorders (PDs) are associated with ‘ways of thinking and feeling about oneself and others, interpersonal functioning, and controlling impulses that significantly and adversely affect how a person functions in many aspects of life’ (American Psychiatric Association 2013, p. 646). A PD is ‘an enduring, pervasive, inflexible and time stable pattern of inner experience and behavior that deviates markedly from the expectations of the individual’s culture, resulting in distress and/or impairment’ (American Psychiatric Association 2013, p. 646).

3.1.6 Current review

The purpose of the current review and meta-analysis was to provide a literature overview of how personality and its dimensions of temperament and character, as well as personality pathology and PDs have been studied in adults with ASD, and to conduct meta-analyses of temperament, character, and PDs in adults with ASD. We first examined participant characteristics like age, gender, diagnosis, IQ, and settings (e.g., psychiatric clinics). We then examined types of measures used to assess temperament, character, and PDs in adults with ASD (i.e., self-report questionnaires and interviews), and the types of statistical methods and results concerning statistical significance in the included studies. We conducted a detailed review of the outcomes and key findings of the included studies. We reported the results of meta-analyses linking temperament and character dimensions, and PDs to adults with ASD. Two West-European studies investigating PD prevalence rates for the general population were included as well: these two studies were selected because PDs in adults with ASD have only been examined in Europe so far. Meta-analyses were performed on each of the TCI dimensions and on each of the ten DSM-IV PDs individually using fixed-effect models due to the small number of included studies (Borenstein et al. 2009, p. 84). In our discussion, we evaluated the outcomes, identified limitations, and suggested future directions for research and clinical practice.

3.2 Methods

3.2.1 Search strategy

This review is based on a systematic search of articles between February 1996 and February 2016. Searches were conducted in two electronic databases: Ovid Medline 1996 to Present, and Embase 1996 to Present, according to the *Preferred Reporting Items for Systematic Reviews and Meta-Analysis* (PRISMA) (Moher et al. 2009). In these databases, the search was limited to articles written in English and published in peer-reviewed journals. The keyword fields in these databases were searched using various forms and combinations of the terms: autism*, autism spectrum disorder*, Asperger syndrome*, pervasive developmental disorder*, personality*, personality disorders*, temperament*, and character*. The asterisk after a term means that all terms that begin with that root were included in the search. After the search, the titles, abstracts, and keywords of the identified articles were screened for possible inclusion. Next, the reference lists of the studies that met inclusion criteria were reviewed to identify additional studies for inclusion. Finally, additional studies were identified by searching the reference list of the studies that met inclusion criteria and which were already known to the first author. Two West-European studies investigating PD prevalence rates for the general population (Barnow et al. 2010; Coid et al. 2006) were identified in Torgersen (2012).

3.2.2 Inclusion and exclusion criteria

Studies were included if they met three inclusion criteria. First, original surveys on adults diagnosed with an ASD based on any DSM (-III, -III-R, -IV, -IV-TR, or -5), aged 16 and over (within a study population of at least adult mean age/18 years), and with a Full Scale IQ or Verbal IQ of 70 and above (without intellectual impairment). In studies in which IQ data were not reported, the participant had to be diagnosed with AS or high-functioning autism (HFA). Second, the study had to examine participants' possible personality (i.e., temperament and character), and/or PD. Finally, the study had to contain systematic data-collection procedures (e.g., structured questionnaires and tests).

Studies were excluded for four reasons. First, studies with adult participants not diagnosed with ASD (Austin 2005; Bejerot et al. 2001; Butler et al. 2015; Eryigit-Madzwamuse et al. 2014; Hurst et al. 2007; Kadak et al. 2015; Kunihiro et al. 2006; Mealey et al. 2014; Picardi et al. 2015; Pisula et al. 2015; Wakabayashi et al. 2006). Second, studies that examined autistic traits in participants with PDs not diagnosed with ASD (Rydén et al. 2008). Third, studies that targeted temperament and character aspects in children and adolescents with ASD (Barger et al. 2014; Barneveld et al. 2011; De Pauw et al. 2011; Kerekes et al. 2013; Schwartz et al. 2009). Finally, a study with adults with ASD already included in an earlier study by the same author (Sizoo et al. 2015) was excluded as it did not yield additional data.

In the end, 15 studies, including one Dutch study with an English abstract by the first author, were selected for inclusion in this review: Anckarsäter et al. (2006), Hesselmark et al. (2015), Hofvander et al. (2009), Kanai et al. (2011ab), Ketelaars et al. (2008), Lugnegård et al. (2012), Ozonoff et al. (2005), Rydén and Bejerot (2008), Schriber et al. (2014), Schwartzman et al. (2016), Sizoo et al. (2009), Söderström et al. (2002), Strunz et al. (2015), and Vuijk et al. (2012). Meta-analyses were performed on each of the TCI dimensions across four studies by Anckarsäter et al. (2006), Sizoo et al. (2009), Soderstrom et al. (2002), and Vuijk et al. (2012), and on each of the 10 DSM-IV PDs individually across four studies by Anckarsäter et al. (2006), Hofvander et al. (2009), Ketelaars et al. (2008), Lugnegård et al. (2012).

3.2.3 Data extraction

The following features of the included studies were extracted: (1) authors, (2) aims of the study, (3) characteristics of participants with ASD (total number of participants, age, sex, setting, country) as well as type of comparison group(s), (4) personality measures used, (5) statistical methods used and results concerning significance, and (6) outcomes. Some studies had several aims, research questions, and outcomes (e.g., Anckarsäter et al. 2006; Hofvander et al. 2009; Kanai et al. 2011b; Ozonoff et al. 2005;

Rydén & Bejerot 2008; Schriber et al. 2014; Hesselmark et al. 2015; Schwartzman et al. 2016): we decided to describe only the aims, research questions, and outcomes relevant to the topic of this review.

The initial literature search in the two databases resulted in a total of 805 records. Excluding duplicates of the 805 records led to a total of 742 unique records. Seven additional records were identified through other sources: three by searching the reference list of the studies that met inclusion criteria (Kanai et al. 2011ab; Wakabayashi et al. 2006) and 4 which were already known to the first author (Austin 2005, Barger et al. 2014; Ozonoff et al. 2005; Picardi et al. 2015). This led to a total of 749 records. Using the inclusion and exclusion criteria, a total of 33 studies of 749 were further screened for possible inclusion on the basis of title, keywords, and abstracts. After this initial screening, 15 studies were identified for possible inclusion. The first and second author applied the inclusion criteria to the list of 15 potential studies. Agreement was obtained on 15 of the 15 studies. See Figure 3.1 for the flow diagram of the search strategy.

After agreement of the list of the studies we included, the first author summarized the studies, independently verified by the second author using a checklist of four questions: (1) is this an accurate description for the topic of our review?, (2) is this an accurate description of included participants?, (3) is this an accurate summary of the results?, and (4) is this an accurate summary of the statistical methods used and classification of significance? There were 60 items on which there could be initial agreement (i.e., 15 studies with four questions per study). Initial agreement was obtained on all items.

3.3 Results

3.3.1 Participants

A total number of 992 persons with ASD participated in the studies, and 991 of them (99.9%) met the inclusion criteria for participants. The sample size of the studies ranged from 15 to 152. Among the 992 included participants, sex was specified for 707 (71.8%): 481 were male (68%), 226 were female (32%). In two studies (Anckarsäter et al. 2006; Ozonoff et al. 2005) sex was not specified for 133 of the participants with ASD. In one study (Schwartzman et al. 2016) sex was only specified for ASD ($n = 152$) and non-ASD ($n = 676$) participants together ($n = 828$; 73% were female, 24% were male, and 3% chose other). The participants ranged in age from 16 to 87 years old. In one study (Vuijk et al. 2012) participants' ages ranged from 15 to 72 years, but this study was nevertheless included because the mean age ($M = 38$ years) met our inclusion criteria: only one participant (15 years) was under the age of 16. Thirty-one participants were diagnosed with Autistic Disorder (3.1%), 463 with AS (46.7%), 181 with PDD-NOS or

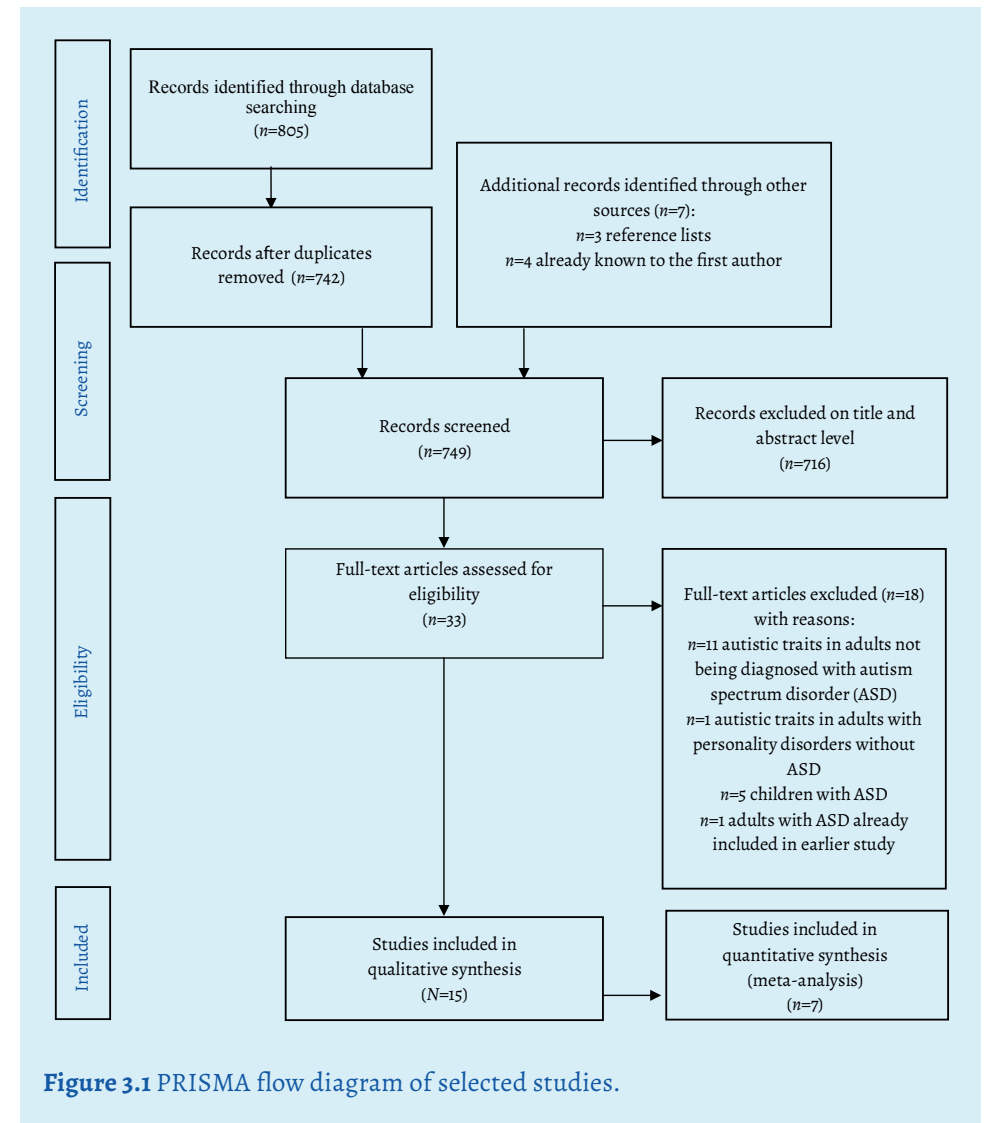


Figure 3.1 PRISMA flow diagram of selected studies.

atypical autism (18.2%), and 317 with high-functioning autism (HFA), or participants were diagnosed with having ASD, classified as AD, AS, or PDD-NOS, but without specified numbers of participants (32%): see Table 3.1. All of the included participants had a Full Scale IQ or Verbal IQ of 70 or above, based on IQ test or level of education.

A total number of controls cannot be given. Four studies used norm groups (Anckarsäter et al. 2006; Sizoo et al. 2009; Soderstrom et al. 2002; Vuijk et al. 2012). Eight studies used non-ASD participants as controls (Hesselmark et al. 2015; Kanai et al. 2011ab; Ketelaars et al. 2008; Ozonoff et al. 2005; Rydén & Bejerot, 2008; Schriber et al. 2014; Strunz et al. 2015). Three studies had no non-ASD control group (Hofvander et al. 2009; Lugnegård et al. 2012; Schwartzman et al. 2016). All controls were age-, sex-, and IQ-/education-matched to the participants with ASD (the experimental group).

Table 3.1 Number of ASD diagnosis of the participants and number of controls in the included studies

	Number of Participants and Controls					Total controls
	AD	AS	PDD-NOS/ Atypical autism	ASD/ HFA	Total ASD	
Söderström et al. (2002)		31			31	Not indicated (norm group)
Ozonoff et al. (2005)				20	20	24
Anckarsäter et al. (2006)	6	46	61		113	Not indicated (norm group)
Ketelaars et al. (2008)		4	10	1	15	21
Rydén & Bejerot (2008)	5	51	28		84	46
Hofvander et al. (2009)	5	62	50		117	None
Sizoo et al. (2009)				75	75	657 (norm group)
Kanai et al. (2011a)		55			55	57
Kanai et al. (2011b)		64			64	65
Lugnegård et al. (2012)		54			54	None
Vuijk et al. (2012)	15	26	27		68	447 (norm group)
Schriber et al. (2014)		21	5	11	37	42
Hesselmark et al. (2015)				48	48	53
Strunz et al. (2015)		49		10	59	248
Schwartzman et al. (2016)				152	152	None
Total	31 (3.1%)	463 (46.7%)	181 (18.2%)	317 (32%)	992	

AD = Autistic disorder; AS = Asperger's disorder; ASD = Autism spectrum disorder; HFA = High-functioning autism, i.e., characterized by cognitively 'higher functioning' (with an IQ of 70 or above) than other people with ASD; PDD-NOS = Pervasive developmental disorder-not otherwise specified.

3.3.2 Settings

The setting was specified in all studies. The most often reported settings were outpatient (neuro)psychiatric clinics (Hofvander et al. 2009; Hesselmark et al. 2015; Kanai et al. 2011ab; Söderström et al. 2002; Rydén & Bejerot 2008; Lugnegård et al. 2012; Strunz et al. 2015; Vuijk et al. 2012) including child and adolescent neuropsychiatric clinics where patients participated in an adult project and where previous patients were recruited (Anckarsäter et al. 2006; Lugnegård et al. 2012; Ozonoff et al. 2005). Outpatient centers of expertise (Ketelaars et al. 2008; Sizoo et al. 2009; Vuijk et al. 2012) were also present. Three studies recruited participants from local physicians, psychologists, speech and language pathologists, occupational therapists, advocating groups, regional centers, ASD support groups, ASD websites, or electronic and paper-based flyers (Hesselmark et al. 2015; Schriber et al. 2014; Schwartzman et al. 2016).

3.3.3 Types of personality measures used in the included studies

A total of 15 personality measures were used across the 15 studies: 67% ($n = 10$) of the studies included one personality measure, 33% ($n = 5$) of the studies included two personality measures. As shown in Table 2, all measures were used by only one study except for three: (1) the *NEO-Personality Inventory-Revised* (NEO-PI-R) was used in two studies (Hesselmark et al. 2015; Strunz et al. 2015); (2) the *Structured Clinical Interview for DSM-IV Personality Disorders* (SCID-II) was used in three studies (Anckarsäter et al. 2006; Hofvander et al. 2009; Lugnegård et al. 2012); and (3) the *Temperament and Character Inventory* (TCI) was used in three studies (Anckarsäter et al. 2006; Söderström et al. 2002; Vuijk et al. 2012). Eighty-seven percent ($n = 13$) of the personality measures were self-report questionnaires, 13% ($n = 2$) were a structured interview. Table 3.2 shows the 15 personality measures used in the included studies.

3.3.4 Statistical methods used and classification of significance

A total of seven statistical methods were used across the 15 studies. Four studies used a one-sample t-test with a cross-sectional design (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012). Four studies used an independent-samples t-test (Hesselmark et al. 2015; Ozonoff et al., 2005; Schriber et al. 2014; Schwartzman et al. 2016). Three studies used a Chi-square test (Hofvander et al. 2009; Ketelaars et al. 2008; Lugnegård et al. 2012). One study used a Kruskal-Wallis test (Rydén & Bejerot 2008), one used a Spearman's rank correlation coefficient (Kanai et al. 2011a), one a Mann-Whitney U-test (Kanai et al. 2011b), and one a MANOVA (Strunz et al. 2015).

Eleven studies (73.3%) reported significant results (Anckarsäter et al. 2006; Hofvander et al. 2009; Kanai et al. 2011ab; Rydén & Bejerot 2008; Schriber et al. 2014; Sizoo et al. 2009; Söderström et al. 2002; Strunz et al. 2015; Schwartzman et al. 2016;

Vuijk et al. 2012). Three studies (20%) reported effect sizes, and exploratory and descriptive results, because of small sample sizes (Ketelaars et al. 2008; Lugnegård et al. 2012; Ozonoff et al. 2005). One study (6.7%) that tested validity and reliability using the NEO-PI-R reported satisfactory results supporting the use of self-reported measures when assessing adults with ASD (Hesselmark et al. 2015).

Table 3.2 Personality measures used in the included studies

Personality measure	Method	Studies that used measure
BFI - Big Five Inventory (John et al. 2008)	Self-report questionnaire	Schriber et al. (2014)
DAPP-BQ - Dimensional Assessment of Personality Pathology-Basic Questionnaire (Livesley & Jackson 2009)	Self-report questionnaire	Strunz et al. (2015)
DSM-IV based clinical interview not specified (unknown author)	Structured interview	Hofvander et al. (2009)
EPQ - Eysenck Personality Questionnaire (Eysenck & Eysenck 1975)	Self-report questionnaire	Kanai et al. (2011a)
IPDE - International Personality Disorder Examination (Loranger et al. 1994)	Self-report questionnaire	Ketelaars et al. (2008)
IPIP-NEO-120 - International Personality Item Pool Representation of the NEO-PI-R (Johnson 2014)	Self-report questionnaire	Schwartzman et al. (2016)
MMPI-2 - Minnesota Multiphasic Personality Inventory - Second edition (Butcher et al. 2001)	Self-report questionnaire	Ozonoff et al. (2016)
NEO-FFI - NEO-Five Factor Inventory (Costa & McCrae 1992)	Self-report questionnaire	Kanai et al. (2011b)
NEO-PI-R - NEO-Personality Inventory-Revised (Costa & McCrae 1992)	Self-report questionnaire	Hesselmark et al. (2015) Strunz et al. (2015)
SCID-II screen - Structured screening for DSM-IV Personality Disorders (First et al. 1997)	Self-report questionnaire	Rydén & Bejerot (2008)
SCID-II - Structured Clinical Interview for DSM-IV Personality Disorders (First et al. 1997)	Structured interview	Anckarsäter et al. (2006) Hofvander et al. (2009) Lugnegård et al. (2012)
SPQ - Schizotypal Personality Questionnaire (Raine 1991)	Self-report questionnaire	Kanai et al. (2011a)
SSP - Swedish Universities Scale of Personality (Gustavsson et al. 2000)	Self-report questionnaire	Rydén & Bejerot (2008)
TCI - Temperament and Character Inventory (Cloninger et al. 1994)	Self-report questionnaire	Söderströmer et al. (2002) Anckarsäter et al. (2006) Vuijk et al. (2012)
VTCI - Short Version of Temperament and Character Inventory (Cloninger et al. 1994)	Self-report questionnaire	Sizoo et al. (2009)

3.3.5 Outcomes and summary of key findings

Table 3.3 provides a summary of aims of study, characteristics of participants with ASD, characteristics of comparison group, personality measures used, statistical methods used and results concerning significance, and the outcomes relevant for the topic of this review for each of the 15 included studies.

Personality pathology and PDs

Rydén and Bejerot (2008) compared personality traits in patients with ASD to a psychiatric control group, and compared differences of personality traits between females and males in the ASD group. This study showed that patients with ASD had significantly more schizotypal and avoidant personality traits, higher rates on Stress-Susceptibility, Embitterment, Detachment, Trait Irritability, and Lack of Assertiveness than controls. Females with ASD scored significantly higher than males on borderline and passive-aggressive traits and on Embitterment and Trait Irritability, showing that individuals with ASD have a gender-specific personality profile.

Schriber et al. (2014) examined whether ASD and typically developing (TD) individuals showed different personality trait levels. Individuals with ASD, both males and females, were significantly more neurotic and less extraverted, agreeable, conscientious, and open to experience. Kanai et al. (2011a) also found significantly higher scores on Neuroticism and lower scores on Extraversion of the EPQ in adults with AS than in controls, corresponding with significantly higher Neuroticism scores of the NEO-FFI, and significant lower Extraversion, Agreeableness, and Conscientiousness scores of the NEO-FFI in adults with AS than in controls in a study by Kanai et al. (2011b). Total score of the AQ correlated with the Extraversion, Openness to Experience, and Conscientiousness subscale scores of the NEO-FFI in adults with AS, but not in controls, and is consistent with the clinical picture of AS (Kanai et al. 2011b). Consistent with Kanai et al. (2011ab) and Schriber et al. (2014), in a study testing the validity and reliability of self-reported data using the NEO-PI-R Hesselmark et al. (2015) and in a study with IPIP-NEO-120 Schwartzman et al. (2016) found higher scores on Neuroticism and lower scores on Extraversion, Agreeableness, Conscientiousness, and Openness to Experience in the ASD group compared with controls. Strunz et al. (2015) found significantly lower scores on the NEO-PI-R scales of Extraversion and Openness to Experience, and significantly higher scores on the DAPP-BQ scales of Inhibitedness and Compulsivity in ASD individuals compared to adults with borderline and narcissistic PDs, and controls.

Ozonoff et al. (2005) administered the MMPI-2 to 20 adults with ASD compared to a group of matched college students. They found large group differences for Introversion, indicating higher scores on scale 0 (Social Introversion) and on Personality Psychopathology Five (PSY-5) scale Introversion for individuals with ASD.

Table 3.3 Summary and analysis of included studies

Study	Aims	ASD participants (<i>n</i> , ASD diagnosis, Age, Sex, IQ, Setting, Country)	Comparison group (<i>n</i> , Age, Sex, Setting)	Personality measures	Statistical methods and results concerning significance	Outcomes relevant to the topic of this study
Söderström et al. (2002)	To study personality characteristics of adults with AS, and to investigate the value of self-rating personality inventories	<i>n</i> = 31 (AS: 31) Age range: 17-55 yrs (Mean: 23 yrs) Sex: 28M, 3F IQ ≥ 85 Setting: Outpatient Child Neuropsychiatric Clinic Country: Sweden	Age- and sex-matched norm groups not further specified	TCI	One-sample t-test Significant results	Adults with AS scored significantly higher on Harm Avoidance, Self-Transcendence, and lower on Novelty Seeking, Reward Dependence, Self-Directedness, Cooperativeness compared to norm group
Ozonoff et al. (2005)	To explore personality psychopathology in patients with ASD compared to matched college students	<i>n</i> = 20 (ASD/HFA: 20) Age range: 18-40 yrs (Mean: 23 yrs) Sex: 85%M, 15%F IQ range: 73-129 Setting: University Child and Adolescent Specialities Clinic Country: USA	<i>n</i> = 24 Age range: 18-29 yrs (Mean 20 yrs) Sex: 75%M, 25%F IQ range: 82-117 Setting: Introductory Psychology Class at University of Utah	MMPI-2	Independent-samples t-test Non-significant results	Patients with ASD scored higher on Depression, Social Introversion, Social Discomfort, Repression and PSY-5 scale Introversion compared to control group
Anckarsäter et al. (2006)	To describe personality development and PDs in relation to symptoms of ADHD and ASD	<i>n</i> = 113 (AD: 6; AS: 46; Atypical autism: 61) (ASD only: 66; ASD-ADHD: 47) Age range: 19-60 yrs (Mean: 31 yrs) Sex/IQ: not specified Setting: Child Neuropsychiatric Clinic Country: Sweden	Age- and sex-matched norm groups not further specified	TCI SCID-II	One-sample t-test Significant results	Patients with ASD reported lower Novelty Seeking and Reward Dependence, higher Harm Avoidance, and lower Self-Directedness and Cooperativeness compared to norm group. Cluster A and C PDs were common in patients with ASD
Ketelaars et al. (2008)	To investigate whether patients with mild ASD and non-ASD differed in terms of AQ-scores and Axis I and II mental disorders	<i>n</i> = 15 (AS: 4; PDD-NOS: 10; HFA: 1) Age range: 18-24.5 yrs (Mean: 22 yrs) Sex: 12M, 3F Mean IQ: 104 Setting: Outpatient Autism Center Country: The Netherlands	<i>n</i> = 21 Age range: 18-55.9 yrs (Mean: 27 yrs) Sex: 18M, 3F Mean IQ: 105 Setting: Outpatient Autism Center	IPDE	Chi-Square test Non-significant results	ASD and non-ASD patients did not differ on individual Axis II PDs
Rydén & Bejerot (2008)	To compare demographical factors, psychiatric comorbidity, and PD traits in patients with ASD to a psychiatric control group, and to compare differences of PD traits between females and males in the ASD group	<i>n</i> = 84 (AD: 5; AS: 51; PDD-NOS: 28) Mean age: 30 yrs Sex: 45M, 39F IQ ≥ 70 Setting: Neuropsychiatry Unit at a hospital Country: Sweden	<i>n</i> = 46 Mean age: 34 yrs Sex: 21M, 25F IQ ≥ 70 Setting: Neuropsychiatry Unit at a hospital	SCID-II SSP	Kruskal-Wallis test Significant results	Patients with ASD had significantly more schizotypal and avoidant PD traits, higher rates on Stress-susceptibility, Embitterment, Detachment, Irritability, and Lack of Assertiveness than controls. Females with ASD scored significantly higher than males with ASD on borderline and passive-aggressive PD traits and on Embitterment and Irritability
Hofvander et al. (2009)	To assess autism symptoms according to the DSM-IV criteria and the Gillberg and Gillberg research criteria, patterns of comorbid psychopathology and psychosocial outcome in normal intelligent adults with ASD	<i>n</i> = 117 (AD: 5; AS: 62; PDD-NOS: 50) Age range: 16-60 yrs (Mean: 29 yrs) Sex: 77M, 40F IQ: normal intelligence Settings: Expert diagnostic centers focused on neuropsychiatric assessments of childhood disorders in adults Country: Sweden	Within comparison group	SCID-II DSM-IV-interview	Chi-Square test Significant results	Obsessive-compulsive PD was significantly more common in the AS group, and antisocial PD in the PDD-NOS group. Frequency of PDs did not differ between men and women, with the exception of schizoid PD, which was significantly more common in females with ASD

Table 3.3 *Continued*

Study	Aims	ASD participants (<i>n</i> , ASD diagnosis, Age, Sex, IQ, Setting, Country)	Comparison group (<i>n</i> , Age, Sex, Setting)	Personality measures	Statistical methods and results concerning significance	Outcomes relevant to the topic of this study
Kanai et al. (2011a)	To examine clinical characteristics of adults with AS	<i>n</i> = 55 (AS: 55) Age range: 18-49 yrs (Mean: 27 yrs) Sex: 36M, 19F Mean IQ: 109.4 Setting: Diagnostic outpatient clinic at a University hospital Country: Japan	<i>n</i> = 57 Age range: 20-52 yrs (Mean: 28 yrs) Sex: 35M, 22F IQ: not indicated Settings: Diagnostic outpatient clinic at a University hospital, several drug companies and a women's college	SPQ EPQ	Spearman's Rank Significant results	Scores on SPQ and the Neuroticism and Psychoticism scores of the EPQ were significantly higher in adults with AS than in controls. The Extraversion and Lie scores of the EPQ were significantly lower in adults with AS than in controls. The total score of the AQ was correlated with three subscale scores (Unusual perceptual experiences, Odd or eccentric behavior, and Suspiciousness) of the SPQ in the AS group, but not in the control group
Kanai et al. (2011b)	To examine clinical characteristics of adults with AS	<i>n</i> = 64 (AS: 64) Age range 19-50 yrs (Mean: 32 yrs) Sex: 50M, 14F IQ range: 92-134 (Mean: 110) Setting: Diagnostic outpatient clinic at a University hospital Country: Japan	<i>n</i> = 65 Age range 19-57 yrs (Mean: 32 yrs) Sex: 52M, 13F IQ: not indicated Setting: Diagnostic outpatient clinic at a University hospital	NEO-FFI	Mann-Whitney U test Significant results	Neuroticism scores of the NEO-FFI were significantly higher in adults with AS than in controls. The Extraversion, Agreeableness, and Conscientiousness scores of the NEO-FFI were significantly lower in adults with AS than in controls. Total score of the AQ correlated with the Extraversion, Openness, and Conscientiousness subscale scores of the NEO-FFI in adults with AS, but not in controls
Lugnegård et al. (2012)	To investigate the presence of possible PDs in young adults with AS	<i>n</i> = 54 (AS: 54) Mean age: 27 yrs Sex: 26M, 28F IQ range: 73-143 (Mean: 102) Settings: Outpatient clinic for adults with ASD and outpatient neuropsychiatric clinic for children adolescents Country: Sweden	Within comparison group (M-F, and ASD with and without a PD)	SCID-II	Chi-Square test Non-significant results	48% fulfilled criteria for a PD, all belonging to clusters A and C. Men with AS met PD criteria much more often than women with AS (65% vs 32%). Participants fulfilling criteria for a PD showed more marked autistic features according to the AQ
Vuijk et al. (2012)	To map personality characteristics of adults with ASD	<i>n</i> = 68 (AD: 15; AS: 26; PDD-NOS: 27) Age range: 15-72 yrs (Mean: 38 yrs) Sex: 68M IQ: at least normal intelligence Settings: Expertise Center for Autism, and Department of Psychiatry at a University hospital Country: The Netherlands	<i>n</i> = 447 Age range: 18-87 yrs (Mean: 44.2 yrs) Sex: 447M IQ: not indicated Setting: Well-defined external control group for TCI assessment	TCI	One-sample t-test Significant results	Compared to the control group, men with ASD scored higher on Harm Avoidance, but lower on Novelty Seeking, Reward Dependence, Self-Directedness, and Cooperativeness
Schriber et al. (2014)	To compare self-reports of Big Five personality traits in adults with ASD to those typically developing adults	<i>n</i> = 37 (AS: 21; PDD-NOS: 5; HFA: 11) Age range: 18-40 yrs (Mean: 22 yrs) Sex: 22%F IQ range: 79-140 (Mean: 108) Settings: local physicians, psychologists, speech and language pathologists, occupational therapists, advocating groups, regional centers and ASD support groups Country: USA	<i>n</i> = 42 Age range: 18-34 yrs (Mean: 23.2 yrs) Sex: 20%F IQ range: 87-136 (Mean: 116) Settings: local physicians, psychologists, speech and language pathologists, occupational therapists, advocating groups, regional centers and ASD support groups	BFI	Independent samples t-test Significant results	Compared to typically developing adults, adults with ASD tended to be significantly more Neurotic, and less Extraverted, Agreeable, Conscientious, and Open to experience

Table 3.3 Continued

Study	Aims	ASD participants (<i>n</i> , ASD diagnosis, Age, Sex, IQ, Setting, Country)	Comparison group (<i>n</i> , Age, Sex, Setting)	Personality measures	Statistical methods and results concerning significance	Outcomes relevant to the topic of this study
Hesselmark et al. (2015)	To test the validity and reliability of self-reported data using the NEO-PI-R in an ASD group	<i>n</i> = 48 (ASD: 48) Age range: 20-47 yrs (Mean: 29.8 yrs) Sex: 26M, 22F IQ: within the average range Settings: Outpatient tertiary psychiatric unit for diagnosing ASD, a community-based facility for ASD, and a Swedish ASD website Country: Sweden	<i>n</i> = 53 Age matched, not specified Sex: 28M, 25F IQ: within the average range Settings: Nonprofit keep-fit organization, local university, student accommodation center, private companies, dentists and vaccination centers, employment agencies, recommendations from friends	NEO-PI-R	Independent samples t-test Significant results	Satisfactory internal consistency of the NEO-P-R, a satisfactory factor structure, predicted correlations with clinician ratings in the ASD group, and predicted differences in personality between the ASD group and controls
Strunz et al. (2015)	To identify personality traits and personality pathology specific to adults with ASD	<i>n</i> = 59 (AS: 49; HFA: 10) Mean age: 32.7 yrs Sex: 27M, 32F IQ: without intellectual impairments Setting: Nonpatient's clinic of Department of Psychiatry at a University hospital Country: Germany	<i>n</i> = 80 (Borderline PD), <i>n</i> = 62 (Narcissistic PD), <i>n</i> = 106 (Nonclinical controls) Mean age: 29.7 yrs for BPD, 36 yrs for NPD, 30.8 yrs for Nonclinical controls Sex: 29M, 31F (BPD); 45M, 17F (NPD); 56M, 50F (Nonclinical controls) IQ: without intellectual impairments Settings: BPD and NPD were outpatient and recruited as part of a multicenter study by Department of Psychiatry at a University hospital; Nonclinical controls via advertisements in local papers	NEO-PI-R DAPP-BQ	MANOVA Significant results	Individuals with ASD scored significantly lower on the NEO-PI-R scales Extraversion and Openness to experience, and significantly higher on DAPP-BQ scales Inhibitedness and Compulsivity relative to all other groups
Schwartzman et al. (2016)	To determine the extent to which the FFM accounts for variability in ASD symptoms in adults, and to examine differences in average FFM personality traits of adults with and without ASD, and to identify distinct behavioral phenotypes within ASD	<i>n</i> = 828 (with and without self-identified ASD; formerly diagnosed with ASD: 152) Age range: 18-87 yrs (Mean: 36 yrs) Sex: 24%M, 73%F, 3%Other IQ: not specified, education ranged from less than high school to professional degree Settings: Recruited via flyers (electronic and paper-based), lists of e-mails, postings on blogs, forums, online classified pages, social network sites (autism-related) Country: USA	Within comparison group	IPIP-NEO	Independent samples t-test Significant results	FFM facets accounted for 70% of variance in autism traits scores. Neuroticism positively correlated with autism symptom severity, while Extraversion, Openness to experience, Agreeableness, and Conscientiousness negatively correlated with autism symptom severity. Four FFM subtypes emerged within adults with ASD, with three subtypes characterized by high Neuroticism, and none by lower-than-average Neuroticism

AD = Autistic Disorder; ADHD = Attention-Deficit/Hyperactivity Disorder; AQ = Autism Spectrum Quotient; AS = Asperger's Disorder; ASD = Autism Spectrum Disorder; BFI = Big Five Inventory; BPD = Borderline Personality Disorder; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders Fourth Edition; EPQ = Eysenck Personality Questionnaire; F = Female; FFM = Five-Factor Model; HFA = High-Functioning Autism; IQ = Intelligence Quotient; IPDE = International Personality Disorder Examination; IPIP-NEO-120 = International Personality Item Pool Representation of the NEO-PI-R; M = Male; MANOVA = Multivariate Analysis of Variance; MMPI-2 = Minnesota Multiphasic Personality Inventory – Second edition; NEO-FFI = NEO Five-Factor Inventory; NEO-PI-R = NEO-Personality Inventory-Revised; NPD = Narcissistic Personality Disorder;

PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified; PDs = Personality Disorder(s); PSY-5 = Personality Psychopathology-Five; SCID-II = Structured Clinical Interview for DSM-IV Axis II Personality Disorders; SPQ = Schizotypal Personality Questionnaire; SSP = Swedish Universities Scales of Personality; SUD = Substance Use Disorder; TCI = Temperament and Character Inventory; VTCI = Short Version of Temperament and Character Inventory

Lugnegård et al. (2012) investigated the presence of possible PDs in 54 young adults with AS and found approximately half of the study group (48%) met criteria for a personality disorder, all belonging to DSM-IV cluster A or C, the same as Anckarsäter et al. (2006) found to be common in their study. Hofvander et al. (2009) found that 62% of 117 adults with ASD met criteria for at least one PD, with obsessive-compulsive PD significantly more common in adults with AS, and antisocial PD in adults with PDD-NOS. Males with AS met PD criteria much more often than females with AS (65% vs 32%) (Lugnegård et al. 2012), and schizoid PD was significantly more common in females than in males with ASD (Hofvander et al. 2009). Participants who met criteria for a PD showed more outspoken autistic features according to the Autism Spectrum Quotient (AQ). Lugnegård et al. (2012) conclude that there is a considerable overlap in symptoms between AS and schizoid, avoidant, and obsessive-compulsive PDs. In a pilot study, Ketelaars et al. (2008) found that self-reporting did not differentiate mild ASD patients from non-ASD patients, whereby PDs seem equally prevalent (47% vs 48%) among these two groups. An important limitation in this latter research was the small number of individuals diagnosed with ASD ($n = 15$), plus that they belonged to the less-severe side of the spectrum.

Results of PDs meta-analysis

Meta-analyses across four European studies (Anckarsäter et al. 2006; Hofvander et al. 2009; Ketelaars et al. 2008; Lugnegård et al. 2012) using SCID-II or IPDE for DSM-IV PDs show adults with ASD meeting criteria for a DSM PD classification. For comparison, DSM-IV PDs prevalence rates for the general European population (Barnow et al. 2010; Coid et al. 2006) are shown as well. Notable are the paranoid (20%), schizoid (24%), schizotypal (14%), avoidant (23%) and obsessive-compulsive (31%) PDs in adults with ASD, both in prevalence percentage as well as compared to the general population ranging from 0% for schizotypal to 5% for obsessive-compulsive PDs. Forest plots can be found in Figures 3.2-4.

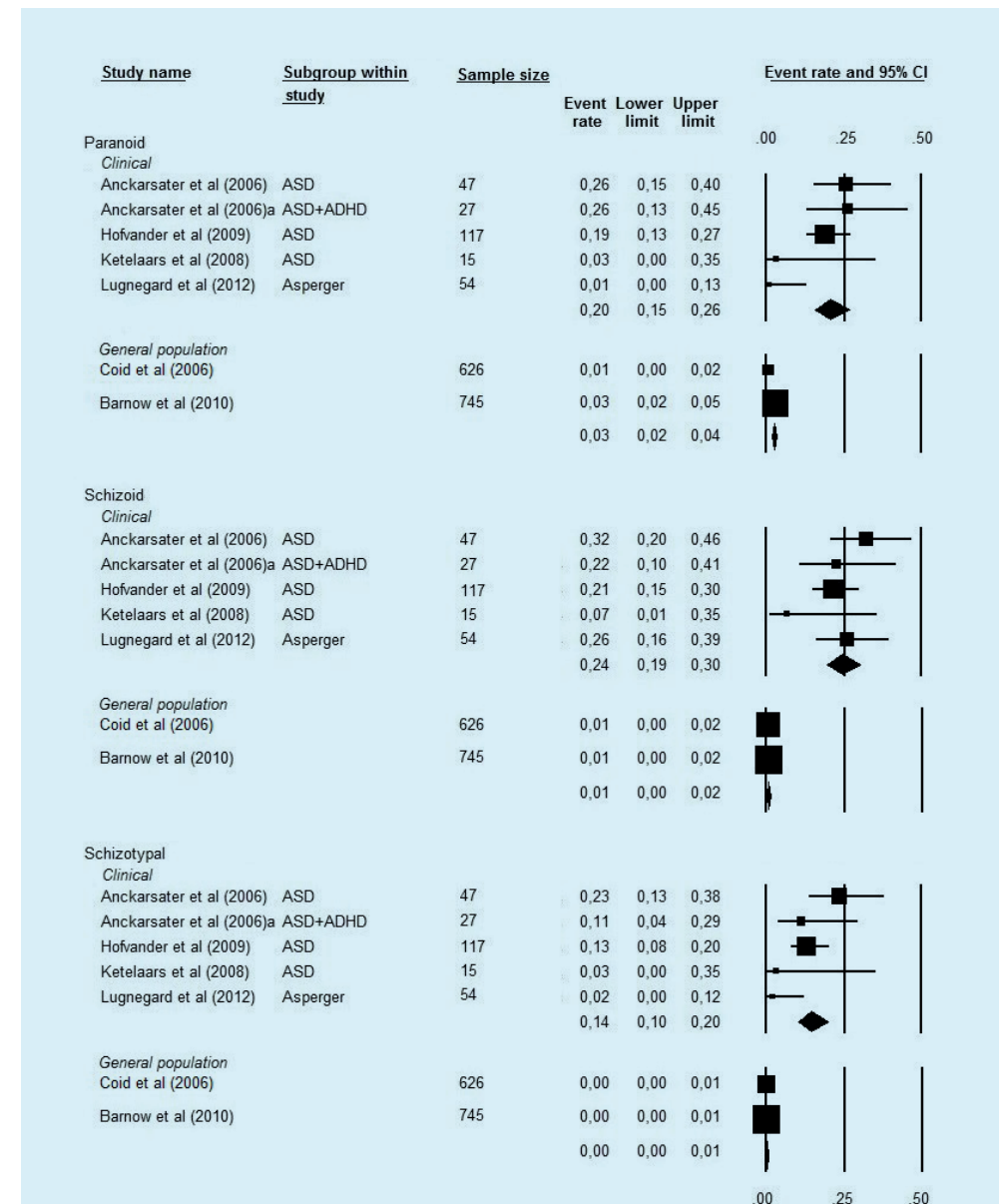


Figure 3.2 Forest plot of the meta-analyses for SCID-II and IPDE DSM-IV cluster A personality disorders in individuals with autism spectrum disorder (ASD) and in general European population.

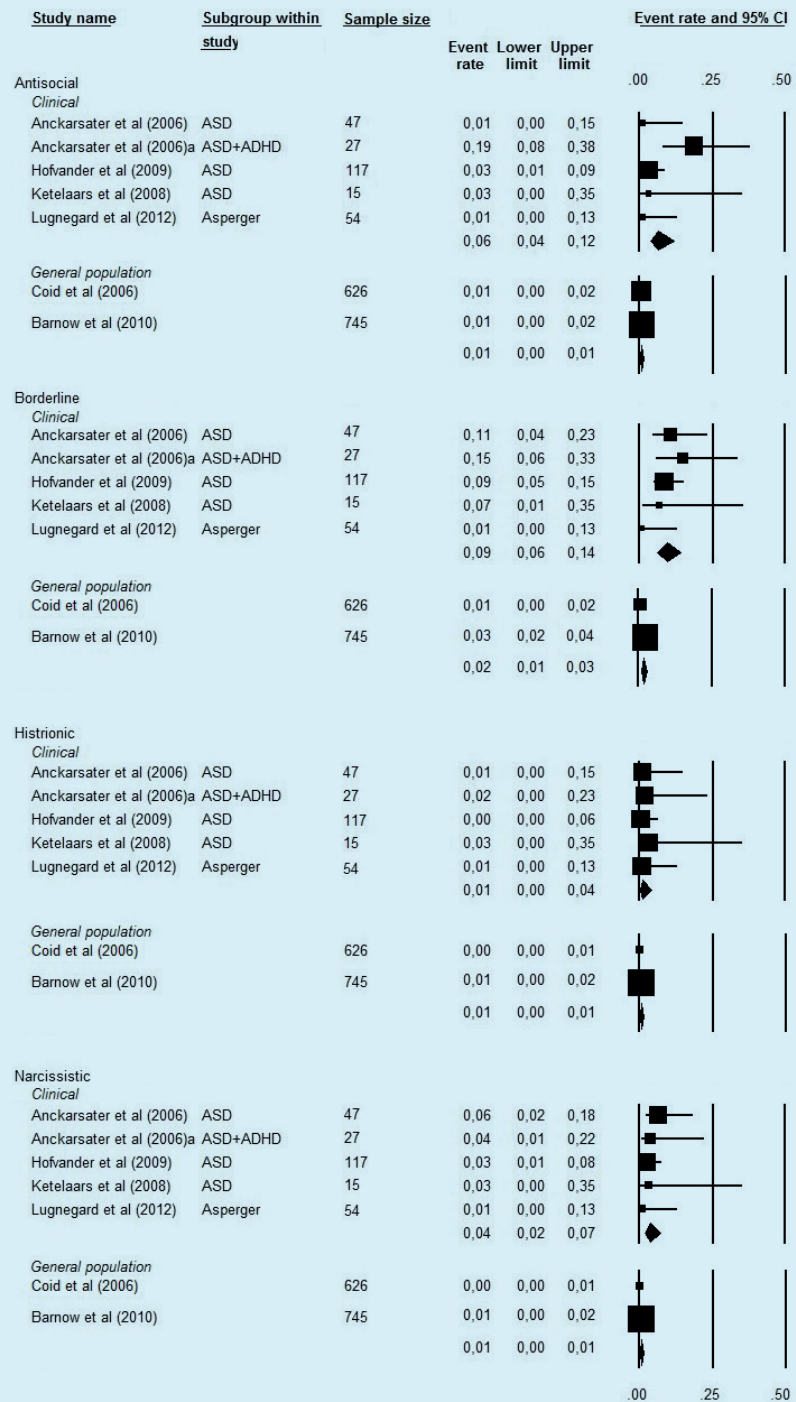


Figure 3.3 Forest plot of the meta-analyses for SCID-II and IPDE DSM-IV cluster B personality disorders in individuals with autism spectrum disorder (ASD) and in general European population.

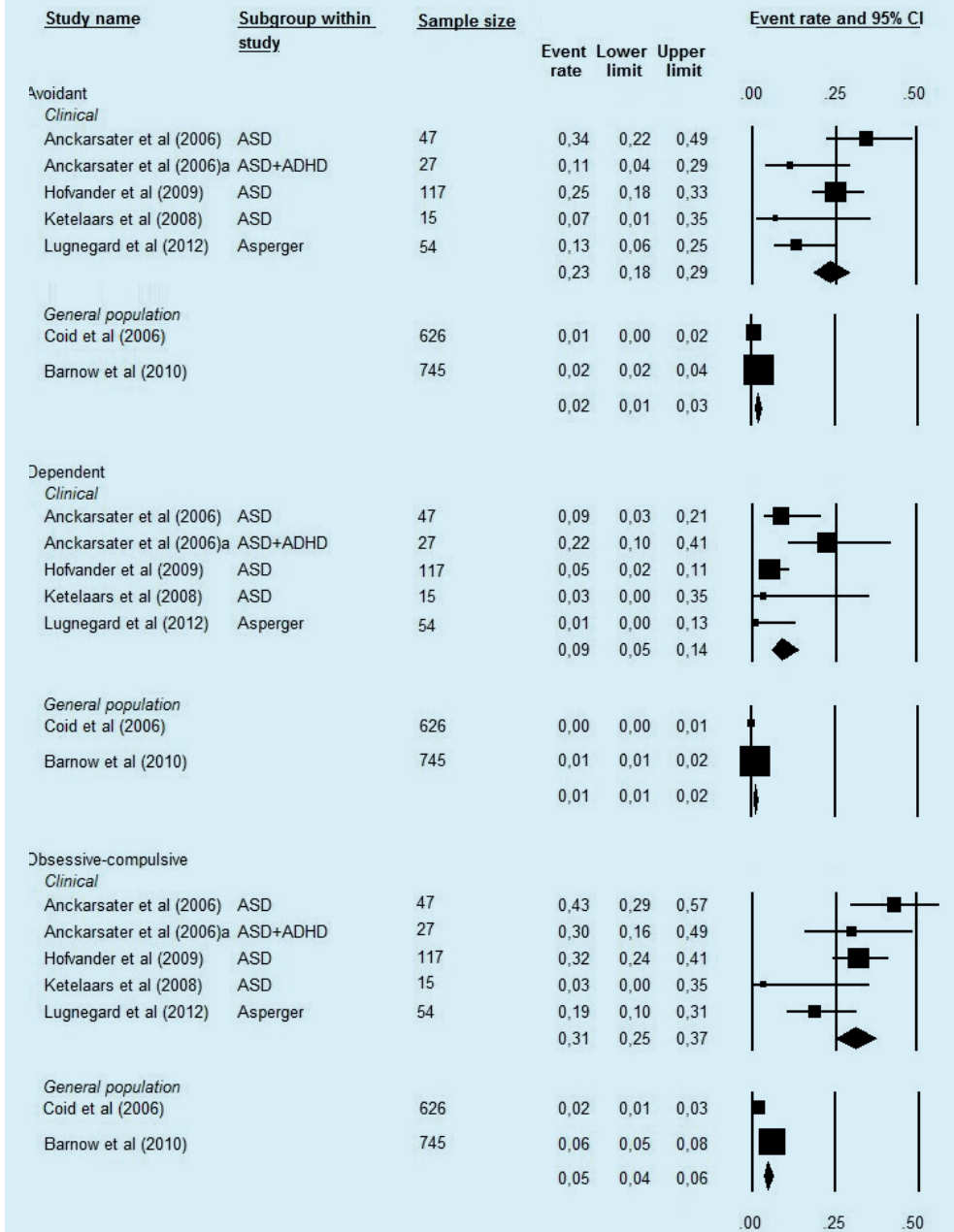


Figure 3.4 Forest plot of the meta-analyses for SCID-II and IPDE DSM-IV cluster C personality disorders in individuals with autism spectrum disorder (ASD) and in general European population.

Results of temperament meta-analysis

Four studies (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012) investigated temperament in adults with ASD by administering them the VTCI/TCI. Meta-analyses (see Figure 3.5) over all the four studies using VTCI/TCI show significant deviances from norm groups ($T = 50$) on the different temperament dimensions for participants with ASD: lower scores on Novelty Seeking ($M = 47.90$; $SD = 10.26$; $d = 0.20$) and Reward Dependence ($M = 42.91$; $SD = 8.5$; $d = 0.83$), and higher scores on Harm Avoidance ($M = 63.39$; $SD = 10.75$; $d = 1.24$) and Persistence ($M = 51.88$; $SD = 10.98$; $d = 0.17$) compared to the norm group. Note that for Persistence, none of the studies individually reported a significant deviance from their norm group. However, when combined in the meta-analysis, the overall 95% confidence interval does not include $T = 50$, denoting the mean of the general population.

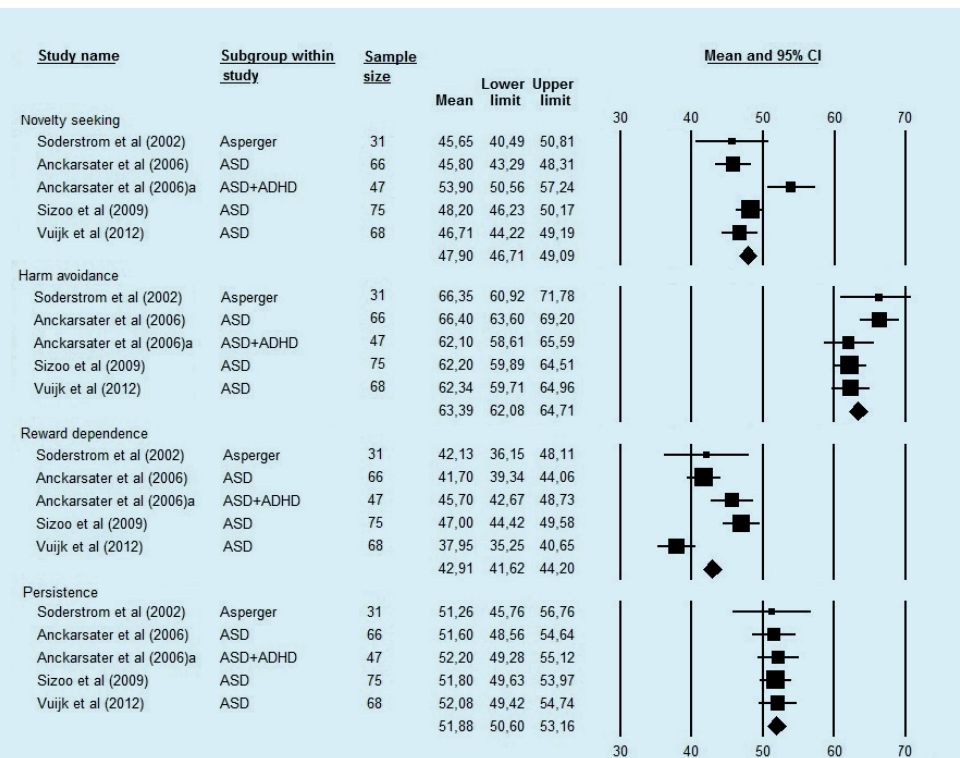


Figure 3.5 Forest plot of the meta-analyses for VTCI/TCI temperament dimensions in individuals with autism spectrum disorder (ASD).

'50' denotes the mean of the general population

Results of character meta-analysis

Four studies (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012) investigated character in adults with ASD by administering them the VTCI/TCI. Meta-analyses (see Figure 3.6) over all the four studies using VTCI/TCI show significant deviances from norm groups ($T = 50$) on the different character dimensions for participants with ASD: lower scores on Self-Directedness ($M = 37.67$; $SD = 12.76$; $d = 0.96$) and Cooperativeness ($M = 41.47$; $SD = 13.96$; $d = 0.61$), and a higher score on Self-Transcendence ($M = 52.06$; $SD = 12.24$; $d = 0.16$) compared to the norm group.

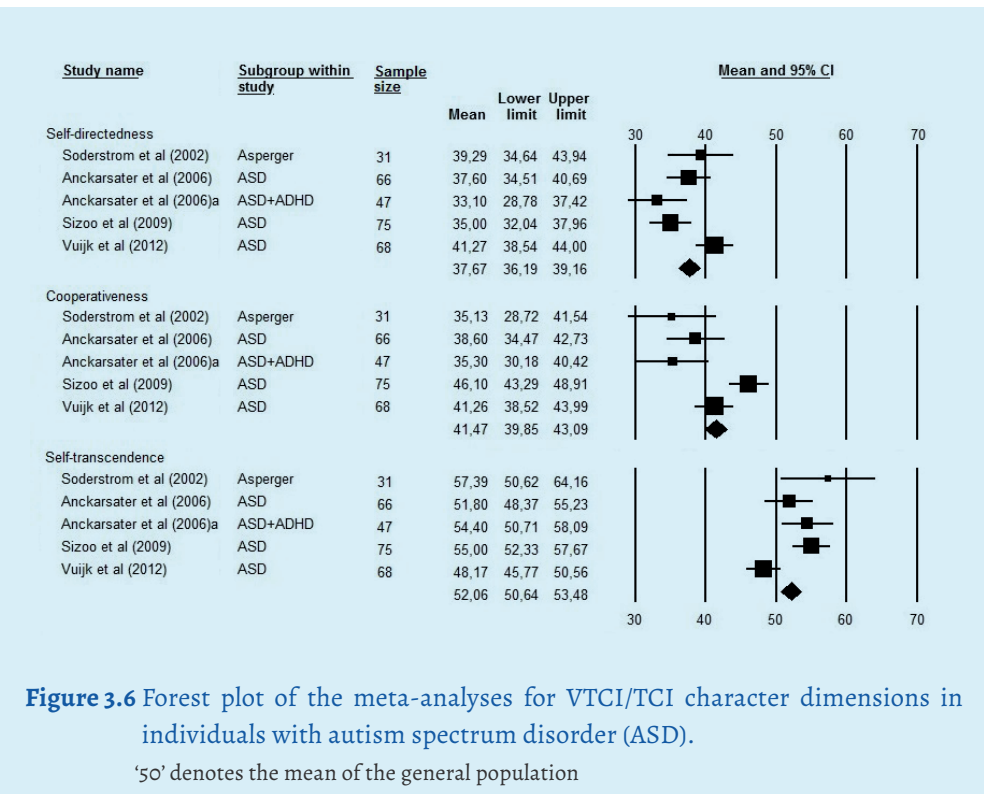


Figure 3.6 Forest plot of the meta-analyses for VTCI/TCI character dimensions in individuals with autism spectrum disorder (ASD).

'50' denotes the mean of the general population

3.4 Discussion

To our knowledge, this literature review of 15 studies is the first to systematically examine temperament, character, personality pathology, and PDs in adults with ASD. Our systematic review summarized 15 studies involving temperament, character, personality pathology, and PDs in normal intelligent adults with ASD.

The systematic review and meta-analysis indicated that ASD is linked to: (1) an introvert, rigid, passive-dependent temperament with low Novelty Seeking, high Harm Avoidance, low Reward Dependence, and high Persistence; (2) an immature and poorly developed character with low Self-Directedness and low Cooperativeness, indicating possible personality pathology, and high Self-Transcendence; (3) a positive correlation between ASD and Neuroticism, and a negative correlation between ASD and Extraversion, Openness to Experience, Agreeableness, and Conscientiousness; and finally (4) PDs, particularly paranoid, schizoid, schizotypal, avoidant, and obsessive-compulsive PDs. Anckarsäter et al. (2006) confirmed with their study that neurodevelopmental disorders like ASD are reflected as challenges in temperament, and are at risk for deficits in character development and PDs, whereby the high Harm Avoidance and low Reward Dependence are described as a typical autism temperament, named as a methodical and obsessive temperament. The pervasive developmental problems in psychosocial functioning in ASD seem to inhibit the maturation of character and personality relevant for interaction with self and others, and is thus reflected by low TCI scores for Self-Directedness and Cooperativeness. Temperament and character may interact with symptoms of ASD leading to individual differences and a variety of both internalizing and externalizing problems among individuals with ASD, like Burrows et al. (2016) also found in their study of children and adolescents with HFA. When ADHD is comorbid in individuals with ASD, they had more ADHD-like temperament with higher Novelty Seeking and Harm Avoidance and lower reward dependence than individuals with ASD only (Anckarsäter et al. 2006). In our meta-analysis, we found a significantly high score on Self-Transcendence, like Sizoo et al. (2009) and Söderström et al. (2002) also found. The high Self-Transcendence scores in combination with low Self-Directedness and low Cooperativeness are an indication for naivety and problems with reality-testing (Cloninger et al. 1993).

The studies in our review yield empirical support for personality variation and diversity in possible comorbid PDs within the ASD group. Different effect sizes (no, weak, medium, and large effect sizes) on temperament and character dimensions ranging from 0.16 (Self-Transcendence) to 1.24 (Harm Avoidance) in the ASD group were found. The far from perfect association between ASD and temperament and character are echoed by the PD-comorbidity findings: although clear associations were found, they were far from perfect (highest PD prevalences in the 25-30%

range), across multiple PDs and even in different DSM-IV clusters (A and C). It can, therefore, be concluded that there is considerable variation in personality and personality pathology in people with ASD. Previous studies have reported similar findings. Schwartzman et al. (2016) found four different personality profiles with different patterns, with three subtypes characterized by high Neuroticism and none characterized by lower-than-average Neuroticism. Schwartzman et al. (2016) view ASD as a set of personality traits on the one hand paralleling the diagnostic or associated characteristics of ASD (e.g., low social reward sensitivity and rigidity), but in other ways a set of non-ASD related personality traits (e.g., anxiety). A first study (Strunz et al. 2015) aimed at differentiating ASD from PDs identified an ASD-specific personality profile with differences in Introversion, Openness to Experience, Conscientiousness, and Dissocial Behavior between people with ASD and with narcissistic and borderline PD. Note however that DSM-IV cluster A and cluster C PD comparisons groups were missing in the Strunz et al. study (2015), while these are the most relevant, given the present findings.

Our meta-analytic results show no (near) 100% prevalence of any specific PD in adults with ASD. Specifically, it is remarkable that DSM-IV and DSM-5 instruct to not diagnose schizoid and schizotypal PDs in individuals with ASD. It is suggested that this is because of an overlap in diagnostic criteria, but then these criteria are not made explicit. Our meta-analysis finds pooled prevalence rates of only 24% for schizoid PD and 14% for schizotypal PD, versus 20% for paranoid PD, 23% for avoidant PD and 31% for obsessive-compulsive PD. For these latter 3 PDs, ASD is remarkably not indicated by DSM as an exclusion criterion, while their prevalence is at least as high in adults with ASD. In our view, the 'relatively' low prevalence rates of schizotypal and schizoid PDs in adults with ASD and the comparable or higher prevalences of three other PDs do not support the DSM-IV and DSM-5 exclusion criterion. It would probably be better to assess all PDs in individuals with ASD when a better understanding of personality pathology is needed in them.

The studies in our review provide empirical support for a co-occurrence of autistic traits, temperament, character, personality pathology, and PDs. ASD and personality pathology may present the same clinical picture with lifelong and pervasive challenges in interpersonal interaction and dimensions of affect. The findings in the reviewed studies demonstrate both a similarity and a variation in clinical phenotypes, also found in studies with a non-ASD population exploring overlaps and correlations between autistic traits and personality (Austin 2005; Barneveld et al. 2011; Hurst et al. 2007; Kunihira et al. 2006; Picardi et al. 2015; Pisula et al. 2015; Wakabayashi et al. 2006). On the basis of significantly found phenotypic correlations with the above TCI temperament and character dimensions in a non-autistic population, Picardi et al.

(2015) suggest that autistic traits and these personality dimensions share common genetic and environmental aetiological factors. However, a correlation of phenotypal variables is not a proof of this.

On the basis of the definition of ASD, temperament, character, personality, and PDs as described in the introduction, we must first conclude they are differently defined concepts. Secondly, according to the studies in our review they both resemble and differ from each other in terms of clinical phenotype. For now, there is simply very little empirical research into these issues, and it might be too early to conclude that neither ASD and personality dimensions share genetic and environmental aetiology, nor that ASD, temperament, character, personality pathology and PDs should be conceptually and diagnostically mutually exclusive (see also De Clercq & De Fruyt 2007; Verhoeff 2015). For clinical practice, we suggest that temperament and character of adults with ASD can be described, and all PD comorbidity (even the co-occurrence of both schizoid and schizotypal PDs) can be classified as well.

3.4.1 Limitations

There are a number of limitations to the reviewed studies that need to be considered when interpreting the results of our review and meta-analyses. The information obtained from the questionnaires in these studies is subject to limitations inherent in self-report. The current review does not assess whether the personality measures are valid or reliable in measuring temperament, character, personality pathology, and PDs in adults with ASD. The results of these types of measures should be interpreted with caution in this population, given that adults with ASD can show a lack of self-reflection and self-understanding (Jackson et al. 2012). On the other hand, there is a growing number of studies supporting the valid and reliable use of self-reports in adults with ASD with intelligence within the average range (Berthoz & Hill 2005; Hesselmark et al. 2015; Schriber et al. 2014; Shipman et al. 2011).

The majority of participants with ASD in the included studies were recruited in psychiatric and health care clinics. The samples could be biased by these participants not representing people with ASD in the general population. The high prevalence of PDs in ASD participants can be an artefact of sampling in psychiatric and health care clinics.

All studies in this review consisted of adult participants with normal intelligence. Therefore the results may not be generalizable to the larger population of individuals with ASD including children and adolescents, and individuals with an IQ below 70 (intellectual disability). Nevertheless, more or less similar TCI-scores for harm avoidance, reward dependence, self-directedness, and cooperativeness have been found in 9 to 12-year-old children (Kerekes et al. 2013).

From the 15 studies, three studies reported effect sizes and exploratory and descriptive results, because of small sample sizes. Replication of our findings in other and larger study groups, including both adults and children and equal numbers of females and males, and a comparison of our findings to children and adolescents are required to examine comorbidity and differences between ASD and personality (pathology), and to better understand the developmental pathways of personality (pathology) in ASD across the lifespan and genders (see also Supekar et al. 2017). Adults with ASD are historically an understudied group, and on this specific topic more research is needed on how to best view, assess, and treat problems with temperament, character, and PD in people with ASD (e.g., Damiano et al. 2014).

3.4.2 Future directions

Overall, the findings that emerge from the included studies show similarities and differences between the concepts of ASD, temperament, character, personality pathology, and PD. The aetiology of these concepts is a topic of interesting dialogues and discussions about how ASD and personality (disorders) will be found to relate in future research. To more accurately classify an individual's disturbed functioning as either ASD or PD or as both in clinical practice, further multidisciplinary longitudinal research is needed to better understand the different developmental pathways and natures of ASD, temperament, character, and PDs. Distinct personality domains have already been shown in ASD parents, suggesting specific personality traits inherited as autistic phenotypes (Kadak et al. 2015).

All studies in this review were cross-sectional, and the key findings and conclusions presented here do not imply causal relationships. Studies examining causal relationships between ASD, temperament, character, and personality, and differentiating ASD from PDs, and studies examining disorder-specific endophenotypical temperament and character dimensions are needed in the future.

Despite the growing recognition and evidence that personality (pathology) is present in people with ASD, many clinicians and researchers do not consider this co-occurrence or comorbidity. More research into this co-occurrence or comorbidity is necessary to gain insight in optimal interaction styles, intervention benefits, and effective treatments.

Treatment for personality disordered ASD individuals has, as far as we know, not been topic of any study, but should be in the near future when considering the picture of personality (pathology) in adults with ASD as provided in this review. Several treatment approaches for PDs in general, usually medium to long-term, offer promising evidence. Future studies should also aim to investigate the treatment of personality (pathology) in adults with ASD (Vuijk & Arntz 2017; see also Chapters 7 and 8).

3.4.3 Conclusion

Results from the present review and meta-analyses show that ASD is significantly associated with several temperament and character dimensions, and with major PDs, yet with such a variation that results indicate a variable instead of uniform personality profile. Taken together and in relation to Cloninger's model, the associations confirmed by our meta-analyses for ASD were for high Harm avoidance, low Novelty Seeking, low Reward Dependence, high Persistence, low Self-Directedness, low Cooperativeness and high Self-Transcendence. In relation to the Five Factor Model, our review finds a positive correlation between ASD and Neuroticism, and negative correlations between ASD and Extraversion, Openness to Experience, Agreeableness, and Conscientiousness. These findings are indicative for an introvert, rigid, and passive-dependent temperament, and an immature and poorly developed character (Söderström et al., 2002). In line with our meta-analytic findings, it is not surprising that studies found people with ASD meeting criteria for a PD, from the DSM-IV cluster A (the odd and eccentric paranoid, schizoid, and schizotypal) and cluster C (the anxious or fearful avoidant, and obsessive-compulsive), and with higher prevalence rates compared to the general population. All findings are consistent with the classic and also heterogeneous clinical picture of ASD we have so far: from the autism-specific social and communication impairments, corresponding with, e.g., low Reward Dependence, less Extraversion and Agreeableness, schizoid and avoidant PDs, to rigid and stereotypical behaviors, corresponding with, e.g., low Novelty Seeking, less Openness to Experience, and obsessive-compulsive PDs. In clinical practice, this makes a diagnostic assessment of ASD complex and difficult: the correspondence of ASD, temperament, character, and PD criteria should be examined by thoroughly exploring the context and the possible developmental pathways of the complaints of an individual suspected of ASD for a well-considered final decision in classifying ASD with or without temperament and character dimensions and PD.

For now, this study provides a more detailed picture of adults with ASD by not only focusing on autism but also on aspects of personality (pathology) and PDs. People with ASD vary, not only in the severity of their autism but also in their personality. This probably accounts for and could advance our understanding of the considerable heterogeneity within the ASD phenotype (De Pauw et al. 2011; Lai & Baron-Cohen 2015; Landry & Chouinard 2016; Schriber et al. 2014; Schwartzman et al. 2016). In order to obtain a comprehensive picture of an individual with ASD and to implement the most effective intervention plans for and therapeutic relationship with adults with ASD, temperament, character, comorbid personality pathology, and PDs should be considered. In line with Vuijk et al. (2012), therapists may consider whether negatively interpreted temperament and character traits can be translated in a positive way in a client's life: e.g., low Novelty Seeking may not only mean less

exploratory excitability (negative), but also less impulsiveness and less disorderliness (positive). Understanding personality can provide insight into strengths and weaknesses of the individual: it can change the perception we have of a person with ASD by not only seeing a person with a pervasive disorder and a classification, but also with a distinct personality (see also Kirchner et al. 2016; De Schipper et al. 2016; Schmidt et al. 2015; Schwartzman et al. 2016; Chapter 4). Adults with ASD are more than just their classification of ASD, and knowing someone's personality gives colour by not only classifying but also characterizing a person, which may be helpful to understanding the individual's idiosyncracies, difficulties, and strengths.

We hope that the present review not only serves clinicians and researchers with an overview of personality and its dimensions of temperament and character, and of personality pathology and PDs in adults with ASD, but that it also inspires researchers in future research and critical reflections on the relationship between these concepts and its impact on assessment and treatment.

4

Temperament and character in males with autism spectrum disorder: A reanalysis of scores on the Temperament and Character Inventory (TCI) by individual case matching

Richard Vuijk, Pieter F.A. de Nijs, Mathijs Deen, Salvatore Vitale, Mirjam Simons-Sprong, Michiel W. Hengeveld

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Abstract

Interest in autism spectrum disorders (ASD) in adulthood is increasing. Although a person may be diagnosed with ASD, the diagnosis reveals little about the individual's temperament, character, and personality. Also, relatively little is known about the personality of adults with ASD. This study aims to reanalyse scores on the *Temperament and Character Inventory* (TCI) administered to a group of 66 normally intelligent males aged 18-63 years, diagnosed with ASD, by individual case matching to a comparison group of 66 males from the general population drawn from the TCI manual. Compared to the comparison group, males with ASD scored significantly higher on the scale for Harm Avoidance, and lower on Novelty Seeking, Reward Dependence, Self-Directedness, and Cooperativeness. In this study, the score pattern for temperament and character found in males with ASD by individual case matching confirms and strengthens previous general group matching findings.

Author contributions

Richard Vuijk, Pieter de Nijs and Michiel Hengeveld designed the study. Richard Vuijk drafted the manuscript, with critical input from the other authors. Richard Vuijk collected the data. Mathijs Deen, Mirjam Simons-Sprong and Richard Vuijk conducted the statistical analyses. All authors read and approved the final manuscript.

4.1 Introduction

There has been growing interest in the personality of individuals diagnosed with an autism spectrum disorder (ASD); this is a neurodevelopmental syndrome with a clinical presentation and characterization of 'persistent deficits in social communication and social interaction, as well as restricted and repetitive patterns of behavior, interests, and/or activities' (American Psychiatric Association 2013, p. 50). The disorder has an estimated prevalence of 1% (Baird et al. 2006; Elsabbagh et al. 2012) and a high prevalence of comorbid psychiatric disorders (Lever & Geurts 2016). Examining personality is more or less a new perspective in the '*multiplicity of autism realities*' (Verhoeff 2015, p. 7), alongside the already familiar ideas about ASD, such as an inability to read other people's minds (Baron-Cohen 1995), a disorder of executive functioning (Hill 2004), a disorder of weak central coherence (Happé & Frith 2006), and an excess of 'systemizing' drives at the expense of 'empathizing' drives (Baron-Cohen 2002), all leading to a spectrum of needs, services, and challenges (Jensen & Cain Spannagel 2011). Dell'Osso et al. (2016) also suggested an *Adult Autism Subthreshold Spectrum* (AdAS) model. that encompasses ASD symptoms, behavioral traits, and personality traits.

Although examining personality in persons with ASD is in its infancy, this is a growing area of research. Recently, specific personality profiles in adults with ASD have been both examined and demonstrated, revealing an interrelatedness between ASD and personality dimensions and traits as well as associations with psychopathology (Sizoo et al 2015; Suh et al. 2016). On the *Five-Factor Model* of personality (Costa & McCrae 1990) positive correlations were found between ASD (severity) and Neuroticism, and negative correlations between ASD (severity) and Extraversion, Openness to Experience, Agreeableness, and Conscientiousness (De Pauw et al. 2010; Hesselmark et al. 2015; Kanai et al. 2011a; Kanai et al. 2011b; Schriber et al. 2014; Schwartzmann et al. 2016; Strunz et al. 2015). In studies examining temperament (largely stable and heritable dimensions of personality) and character (the environmental dimension of personality), ASD has been linked to an introvert, rigid, passive-dependent temperament and a poorly developed character (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002), indicating a risk for personality disorder (PD). Studies examining PD comorbidity in adults with ASD found high prevalence rates for especially DSM-IV cluster A and C PDs (Anckarsäter et al. 2006; Hofvander et al. 2009; Ketelaars et al. 2008; Lugnegård et al. 2012), ranging from 48% (Lugnegård et al. 2012) to 62% (Hofvander et al. 2009). To our knowledge, Kirchner et al. (2016) were among the first to examine character strengths in adults with ASD, finding open-mindedness, authenticity, love of learning, creativity, and fairness as the most frequent signature strengths.

Identifying personality traits might help to: (1) explain the heterogeneity in the functioning of persons with ASD (Burrows et al. 2016), (2) contribute to recognizing both the strengths and weaknesses of these individuals, and (3) may be of added value for the development of new treatment strategies and interaction styles (Koenig et al. 2011). Understanding personality can lead to a different perception of a person with ASD, i.e., by not merely seeing someone who has an ASD classification, but also seeing an individual with a distinct personality.

4.2 The present study

Based on a study we published in a Dutch journal (Vuijk et al. 2012) and on three previous studies in which ASD male participants were generally group matched (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002), we wanted to know if same results would be obtained by individual case matching. We, thus, hypothesized that males with ASD would score differently on the *Temperament and Character Inventory* (TCI; Cloninger et al. 1993) compared to a comparison group: i.e., (1) lower on Novelty Seeking, (2) higher on Harm Avoidance, (3) lower on Reward Dependence, (4) lower on Self-Directedness, and (5) lower on Cooperativeness.

This study, a reanalysis of our 2012 data set, aimed to fill a gap in investigating self-rated temperament and character dimensions in a relatively large group of males with ASD, *individually* matched as closely as possible on age, education, and marital status to a comparison group of males, and sought to confirm and strengthen previous findings from our study published in Dutch (Vuijk et al. 2012) as well as TCI studies from Anckarsäter et al. (2006), Sizoo et al. (2009), and Söderström et al. (2002) in male adults with ASD who were *generally* matched to a norm group.

4.3 Methods

4.3.1 Participants

The ASD group consisted of 66 males, aged 18-63 (mean 38) years, with an IQ of at least 85, and/or having attended primary school for at least eight years. All were diagnosed for the first time with a DSM-IV-TR (American Psychiatric Association 2000) pervasive developmental disorder during an ASD assessment by psychiatrists and psychologists specialized in ASD assessment (the latter supervised by RV from Sarr Autism Rotterdam, or by SV from Erasmus MC, Department of Psychiatry).

The diagnosis of ASD was based on three in-person interview sessions, plus one or two sessions of interviewing the adult's childhood caregiver and/or partner (if applicable) exploring the symptoms in terms of the DSM criteria (for ASD as well as

for other psychiatric disorders). ASD symptoms were also observed and checked in interaction between the participant and the psychologist and the psychiatrist during the three in-person interview sessions. In a fourth session with the participant, the TCI was a standard part of the assessment to acquire an impression of temperament and character. Finally, in each case, the ASD diagnosis was assigned by one of the two authors (RV, SV), both specialized in ASD in adults, after consensus discussions with the psychiatrists and the psychologists.

Table 4.1 presents demographic information on the participants and the comparison group. The majority of participants were Caucasian Dutch (98.5%); 50% were single and 35% had a partner (15% unknown). Educational levels ranged from elementary school (3.0%) to university (7.8%), with the majority having followed lower secondary education (34.8%). In terms of comorbidity, five (7.6%) participants were diagnosed with PD, five (7.6%) with partner-relational problems, four (6.1%) with attention-deficit/hyperactivity disorder (ADHD), two (3.0%) with depressive disorder, and one (1.5%) with psychotic disorder.

The comparison group was a well-defined group drawn from a norm group available in the Dutch manual of the TCI (Duijsens & Spinhoven 2004) individually matched with the ASD group. The comparison group consisted of males from the general population resident in the Netherlands and Flanders (n=66), mean age 39 (SD 11.84, range 20-63) years, matched on age, education, and marital status with the ASD group.

In comparison to our 2012 study, in this study we made the two groups more similar demographically, with equal sample sizes and matched (as closely as possible) on age, marital status, and education. If more matches on age, marital status, and education were available, or if there was no unique match, a random number generator was used to select between the available matches. Although statistical methods are available to match between two groups (e.g., propensity score matching), the matched variables were not defined in exactly the same way. Therefore, we matched using a random number generator.

Table 4.1 Characteristics of males with ASD and the matched comparison group

	ASD group	Comparison group
Age in years: mean, range (SD)	38, 18-63 (12.5)	39, 20-63 (11.84)
Male gender, <i>n</i>	66	66
Ethnicity, <i>n</i> (%)		
Caucasian	65 (98.5%)	66 (100%)
Asian	1 (1.5%)	-
Marital status, <i>n</i> (%)		
Married	20 (30.3%)	43 (65.0%)
Living together	3 (4.5%)	9 (13.6%)
No partner	33 (50.0%)	12 (18.2%)
Unknown	10 (15.2%)	2 (3.0%)
Education, <i>n</i> (%)		
Elementary school only	2 (3.0%)	2 (3.0%)
Lower secondary education	23 (34.8%)	23 (34.8%)
Lower vocational education	14 (21.2%)	15 (22.7%)
Upper secondary school	9 (13.6%)	9 (13.6%)
Higher vocational education	11 (16.7%)	11 (16.7%)
University	5 (7.8%)	6 (9.1%)
Unknown (IQ \geq 85)	2 (3.0%)	-
ASD diagnosis, <i>n</i> (%)		
Autistic Disorder	15 (22.7%)	-
Asperger's Disorder	25 (37.9%)	-
PDD-NOS	26 (39.4%)	-
Comorbidity, <i>n</i> (%)		
Personality Disorder	5 (7.6%)	-
Partner relational problems	5 (7.6%)	-
ADHD	4 (6.1%)	-
Depressive Disorder	2 (3.0%)	-
Psychotic Disorder	1 (1.5%)	-

ADHD = Attention-deficit/hyperactivity disorder; ASD = Autism spectrum disorder; PDD-NOS = Pervasive developmental disorder-not otherwise specified.

4.3.2 Measures

The Dutch (translated) version of the *Temperament and Character Inventory* (TCI; Cloninger et al. 1993) is a self-report questionnaire to determine differences between individuals on seven dimensions of temperament and character, based on Cloninger's psychobiological theory of personality (Cloninger et al. 1993). The TCI consists of 240 items (true/false), four temperament scales (Novelty Seeking, Harm Avoidance, Reward Dependence, and Persistence), three character scales (Self-Directedness, Cooperativeness, and Self-Transcendence), and 25 subscales.

Novelty Seeking is associated with exploratory activity in response to a novel stimulation, impulsive decision-making, extravagance, and disorderliness. Harm Avoidance is characterized by excessive worrying, pessimism, shyness, being fearful, and easily fatigued, with introversion at one end and extraversion at the other end of the spectrum. Reward Dependence is a tendency to respond to signals of reward of social approval, social support, and sentiment. Persistence refers to perseverance in

spite of fatigue or frustration. Self-Directedness is the ability to regulate and adapt behavior to the demands of a situation in order to achieve personally chosen goals and values. Cooperativeness is the degree to which a person is generally agreeable in relationships with other persons, as opposed to aggressively self-centered and hostile. Self-Transcendence is associated with experiencing spiritual ideas, such as considering oneself an integral part of the universe.

The TCI has strong test-retest reliability. Despite the assumption that people with ASD lack insight into their own functioning so that standardized self-report measures may be unsuitable for individuals with ASD (Bishop & Seltzer 2012), studies have shown that they are able to complete self-report questionnaires producing a realistic picture of their functioning (Hesselmark et al. 2015; Schriber et al. 2014; Burrows et al. 2016).

4.3.3 Procedure

Data on the ASD participants were collected during a regular ASD assessment at Sarr Autism Rotterdam, and at Erasmus MC, Department of Psychiatry, between April 2007 and June 2010. All participants filled out the TCI by computer, with instructions provided by a psychologist specialized in ASD assessments. During this period, all participants were informed that data might be used for research purposes, and were given the possibility to refuse or withdraw.

The study procedure was reviewed and approved in an advisory statement by the Medical Ethics Committee of Erasmus MC, Rotterdam, the Netherlands (MEC-2008-221, approved on 24 July 2008). In 2016 we contacted DATEC (the provider of the TCI in the Netherlands), and they offered us the raw data of the comparison group for reanalysing our 2012 data set.

4.3.4 Statistical analysis

After assessing normality for the TCI scales for both groups using histograms, paired samples *t*-tests were used to compare the mean scores of the ASD group with those of the comparison group. SPSS software (version 25) was used to perform the analyses. The TCI was scored comparing the raw scores for each dimension to the scores of the comparison group drawn from the Dutch TCI manual (individually matched on age, education and marital status with the ASD group).

First, we used alpha 0.05. Second, the correcting for multiple comparisons and to control for chance capitalization, Bonferroni corrections were applied to the TCI scores leading to an alpha level of $0.05/7=0.007$.

4.4 Results

Compared to the comparison group, males with ASD (1) scored significantly lower on Novelty Seeking, Reward Dependence, Self-Directedness, and Cooperativeness; (2) significantly higher on Harm Avoidance; and (3) did not score differently from the norm group on Persistence and Self-Transcendence (Table 4.2).

When Bonferroni corrections were applied to the TCI temperament and character scores to control for chance capitalization (leading to an alpha level of $0.05/7=0.007$), the same significant differences were found between the ASD group and the comparison group.

Table 4.2 TCI scores of males with ASD compared to the comparison group

Scale	ASD group			Comparison group			Test statistics			
	M	SD	Range	M	SD	Range	t	df	p	d
NS	16.00	6.04	2-31	20.17	5.87	7-34	-3.71	65	<.001	-0.70
HA	21.73	7.04	7-35	11.88	6.81	0-28	7.61	65	<.001	1.42
RD	11.05	4.16	3-19	14.42	3.78	6-12	-5.10	65	<.001	-0.85
PS	4.89	2.13	1-12	4.70	2.00	1-8	0.62	65	.54	0.10
SD	26.18	7.94	8-42	32.34	7.29	13-42	-4.67	65	<.001	-0.81
CO	27.09	7.12	11-39	31.00	6.52	13-40	-3.56	65	<.001	-0.57
ST	10.86	6.61	2-29	10.71	6.04	1-27	0.14	65	.89	0.02

ASD = Autism spectrum disorder; CO = Cooperativeness; HA = Harm Avoidance; NS = Novelty Seeking; PS = Persistence; RD = Reward Dependence; SD = Self-Directedness; ST = Self-Transcendence; TCI = Temperament and Character Inventory.

4.5 Discussion

The present study, a reanalysis of our 2012 data set, investigated temperament and character dimensions of males with ASD by individual case matching to a comparison group. The results indicate substantial associations between ASD and five of the seven personality dimensions of Cloninger's psychobiological theory of personality (Vuijk et al. 2018; see Chapter 3): low Novelty Seeking, low Reward Dependence, low Self-Directedness, low Cooperativeness and high Harm Avoidance, whereas levels of Persistence and Self-Transcendence did not differ between the two groups. This study, with a strong design of *individual* case matching, confirms and strengthens the findings of previous studies employing *general* group matching (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012), all showing clear differences in temperament and character of the ASD male group compared to the male norm group. For meta-analytic results of these TCI studies (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012) we refer to Vuijk et al. (2018; see Chapter 3).

In brief, the TCI provides a dimensional description of an individual's personality, whereby low and high TCI scores can be interpreted in terms of both negative and positive aspects of temperament and character (Cloninger et al. 1993). Thus, males with ASD have a low score on Novelty Seeking; individuals with a low score on Novelty Seeking can be described as stoic, rigid, reserved and inflexible, as well as being thoughtful, not taking impulsive decisions and being able to maintain routines or practices (Cloninger et al. 1993). In a general population sample of adults, Romero-Martínez et al. (2015) found an inverse association between experience seeking and the specific autistic traits of 'preference for routine' and 'imagination impairment'. Males with ASD have a high score on Harm Avoidance, which is characterized by excessive worrying, pessimism, and shyness; the advantages of high Harm Avoidance are paying attention to possible dangers and avoiding risks, as well as planning and preparing activities carefully (Cloninger et al. 1993). Males with ASD have a low Reward Dependence, which is an indication for being practical and socially insensitive, as well as being independent from sentimental considerations (Cloninger et al. 1993). Izuma et al. (2011) found an insensitivity to social reputation in adults with ASD, with less tendency to adapt their behavior for a better social reputation, just presenting themselves in an authentic and genuine way. Males with ASD have a low score on Self-Directedness, described as immature and in need for support in everyday life (Cloninger et al. 1993); low Self-Directedness can be favorable in certain professional situations with a clear hierarchy and clear leadership, where one has to follow the orders/instructions given by the leader. Finally, males with ASD have a low score on Cooperativeness, often described as being self-centered, not always aware of other people's need for help, ignoring or neglecting the feelings of others and having a possible contentment in being alone (Cloninger et al. 1993).

Several limitations of this study need to be addressed. First, this study included only males with ASD, which was also the case in previous studies. Therefore, and because of the ASD gender subgrouping (Halladay et al. 2015; Supekar et al. 2017; Ypma et al. 2016), the results cannot necessarily be extrapolated to females. Second, the group of participants was heterogeneous in terms of age (participants' age ranged from 18-63 years). Our rationale for choosing this heterogeneity was to be in accordance with the heterogeneity of the comparison group. We are aware that personality scores can change with increasing age and that the differences found can be a trivial artefact of a mean age difference in the scores between the two groups. However, more or less similar TCI scores for Harm Avoidance, Reward Dependence, Self-Directedness and Cooperativeness were found in nine- and 12-year-old children with ASD (Kerekes et al. 2013), suggesting a stable pattern of temperament and character dimensions in persons with ASD over time. Still, the results apply to adults with ASD and cannot necessarily be applied to individuals with ASD under 18 years of age. Third, a clinical control group was lacking. Fourth, although a specific

personality profile indicating personality pathology (low Self-Directedness and low Cooperativeness) was found in these participants with ASD, caution is required when interpreting such results in the context of individual psychological assessments: interpretation in terms of negative as well as positive aspects of temperament and character should be considered (as emphasized in our Discussion).

Clinical implications of this study include the formation of a comprehensive image of individuals with ASD, enriching and deepening our understanding of the person behind the disorder, and developing more effective treatment strategies. Vuijk and Arntz (2017) recently started a study on the treatment of adults with ASD and PD by testing a specific Schema Therapy program: this is a first study focusing not only on ASD but also on personality (pathology) (see Chapters 7 and 8). Further research is required on the temperament and character dimensions of both males and females with ASD, covering the entire range of ages, to improve knowledge on the relationships, the overlap and the differences between these concepts, as well as our understanding of individuals with ASD and their way of functioning in daily life and experiencing the world. It remains difficult to determine whether specific temperament and character configurations increase the risk for ASD, or whether the presence of ASD influences the development of specific temperament and character configurations, or whether (from a dimensional view of psychopathology) these concepts are differently defined but the same phenomena.

4.6 Conclusion

In conclusion, this study investigating males with ASD individually matched to a comparison group, found a temperament with low Novelty Seeking, high Harm Avoidance and low Reward Dependence, and a character with low Self-Directedness and low Cooperativeness, confirming and strengthening the same findings by general group matching in previous studies. People with ASD are of course more than merely their classification of ASD; insight into an individual's personality can lead to a different perception of a person with ASD, i.e., by not merely seeing someone who has an ASD classification, but also seeing an individual with a distinct personality.

5

An explorative study of atypical social interaction styles in adult males with autism spectrum disorder, males with personality disorders, and males from the general population

Richard Vuijk, Mathijs Deen, Arnoud Arntz, Hilde M. Geurts

5

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Abstract

Different atypical social interaction styles (SISs) were defined and tested in children and adolescents with autism spectrum disorder (ASD). Whether these styles can also be distinguished in adults with ASD has not yet been explored. In males with ASD, males with personality disorder (PD), and males from the general population (N = 90), aged 18-65 years, we tested which SISs can be distinguished and how they relate to the presence of PD traits. We found a significant distinction in allocation to atypical SISs between the three groups. This study shows the presence of atypical SISs in adult males with ASD, and complements previous SIS findings in children and adolescents with ASD.

Author contributions

All authors contributed to the study conception and design. Material preparation, and data collection was performed by Richard Vuijk. Data analyses were performed by Richard Vuijk and Arnoud Arntz and checked by the rest of the authors. The first draft of the manuscript was written by Richard Vuijk and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

5.1 Introduction

Autism spectrum disorder (ASD; American Psychiatric Association 2013) is called a spectrum disorder, because of the variation in the type and severity of features, and intellectual functioning contributing to heterogeneity amongst individuals with ASD (Lai et al. 2013). This heterogeneity is considered to be a complicating factor in discriminating the best services, treatments, and needs for autistic individuals (Masi et al. 2017; Rutter & Schopler 1992). Reducing the heterogeneity of the autism spectrum into meaningful, more homogeneous categories has been proposed by researchers and clinicians alike (e.g., Barnoux et al. 2020; Begeer et al. 2015; Bishop et al. 2016).

One attempt in determining more homogeneous categories in, for example, atypical social interaction, one of the core features of ASD, is the *Wing's Subgrouping Scheme*, developed by Wing and Gould (1979), the first known set of descriptions of social interaction styles (SISs). This scheme was designed to determine the SIS of children and adolescents with ASD ranging from social aloofness to awkward social approaches. By following this scheme, one could subdivide individuals with ASD into one of the three SISs (aloof, passive, and active-but-odd) pertaining to the quality of social interaction as perceived by non-autistic others. A fourth SIS was added by Shah (1988), which is called stilted interaction. According to the SIS classifications, aloof individuals seem to reject most social contact and do not respond socially to the approaches of others, have little eye contact, engage in behaviors often perceived as inappropriate, and are usually nonverbal. Passive individuals seem to lack spontaneous approaches to others as well, but respond to the social initiatives of others as long as the other person structures the interaction. Active-but-odd individuals are interacting with others on their own initiative, but their interaction style is often perceived as unusual, peculiar, naïve, and persistent. Stilted individuals tend to be within the non-autistic range of social abilities, showing politeness and strict conventionality with a somewhat formal or even pompous speech. A four-year follow-up study observed that a majority (69%) of children and adolescents with ASD without intellectual disability showed developmental stability in their passive and active-but-odd SISs (Scheeren et al. 2020). In this study, very few children with an aloof SIS and no children with a stilted SIS participated. Another longitudinal follow-up study found 75% of children and adolescents with intellectual disabilities and/or ASD remaining stable in SIS over time (Beadle-Brown et al. 2002). When the SIS of children and adolescents is determined with the *Wing Subgroups Questionnaire* (Castelloe & Dawson 1993), it was shown that the active-but-odd SIS positively associated with features of ASD, attention deficit and hyperactivity, and executive functioning problems, and negatively associated with psycho-social health (Scheeren et al. 2012). Moreover, most studies found the active-but-odd SIS to be associated

with lower ASD severity rates compared to the aloof and passive SISs (Roeyers 1997; Scheeren et al. 2020; Waterhouse et al. 1996). Thus one can make a distinction between SIS within individuals with ASD, but the fact this can be done, does not automatically imply it is also informative to do so as subgrouping people can have a negative impact as well.

However, classifying and knowing atypical SIS in an individual with ASD can actually be useful for a number of reasons. First, every atypical SIS has its own interpersonal challenging way of communicating and interacting with others. Second, for people with atypical SISs needs for interventions likely differ as well as the responsiveness to interventions (Beglinger & Smith 2005). Third, as non-autistic individuals exhibit mind-blindness towards individuals with ASD (Edey et al. 2016), knowing the specific atypical SIS of a person with ASD might, therefore, lead to a better understanding of atypical expressions, leading to less mutual interactional frustration. Several forms of atypical social communication have already been associated with positive first impressions among youth with ASD (Granieri et al. 2020).

Another concept concerning social interaction, and contributing to the heterogeneity in ASD as well, is personality disorder (PD). One of the main criteria for a PD is having a problem in interpersonal functioning (American Psychiatric Association 2013). Typical examples are a solitary lifestyle, conflictual, and distressful social relations, and lack of social support (Hengartner et al. 2014). PDs as well as ASD are associated with a long-term pattern of difficulties in interpersonal functioning: ASD interpersonal challenges as a neurodevelopmental condition, and PD interpersonal challenges based on a combination of a vulnerable temperament and early problematic relations with others, attachment pathology and/or stressful situations or events. There is an increased recognition of specific personality pathology in adults with ASD. Personality pathology in adults with ASD ranges from an introverted, rigid and passive-dependent temperament and a likelihood of atypical character maturation to meeting criteria for PD (Söderström et al. 2002; Vuijk et al. 2018). For a number of reasons knowledge of PDs in adults with ASD can be important. First, PDs in general seem to have a significant impact on psychosocial functioning and negatively affect course, treatment outcomes and the therapeutic relationship (George et al. 2018; Tyrer et al. 2015). Second, PDs require specific interventions and therapeutic strategies like the establishment of a favorable treatment alliance, specific psychoeducation, increasing the client's self-knowledge, planning realistic treatment goals, and matching therapy to the client's personality (Bach & First 2018).

So far studies of the atypical SISs (active-but-odd, passive, aloof, stilted) in ASD focused on children and adolescents. To the best of our knowledge, the atypical SISs has not been studied in adults with ASD. We do not know whether (a) atypical SISs

apply to adults with ASD, (b) whether atypical SISs are associated with DSM-5 PD traits, and (c) whether atypical SISs are associated with demographic characteristics as level of education and having a relationship.

5.2 The present study

The aim of the present study was to explore the presence of atypical SISs in adult males with ASD with or without PD (traits) compared to males with a PD without ASD and to males from the general population (i.e., without ASD and without a PD). As this is a first exploratory study, we have for now solely included males to limit heterogeneity affected by sex differences in phenotypic presentation between males and females with ASD (Loomes et al. 2017; Wilson et al. 2016). Our research questions were: (1) How are the atypical SISs distributed over males with ASD, males with a PD, and males without ASD and without a PD?, (2) What is the relationship between atypical SISs and DSM-5 PD traits?, (3) What is the relationship between the atypical SISs and level of education and having a relationship?

5.3 Methods

5.3.1 Setting

Sarr Autism Rotterdam, Parnassia Psychiatric Institute, the Netherlands, is specialized in psychodiagnostic assessments and interventions for children, adolescents and adults with ASD. Parnassia Psychiatric Institute is a multi-site mental health institute specialized in psychodiagnostic assessments and interventions for children, adolescents and adults with a broad range of psychiatric disorders including PD.

5.3.2 Participants

We included the same sample of participants as in Vuijk et al. (2021). For a full description of the sample recruitment, inclusion, and exclusion criteria, we refer to Vuijk et al. (2021) and Chapter 2.

Participants of the ASD group were included with a primary diagnosis of DSM-IV Autistic Disorder (AD) or Asperger's Disorder (AS) (American Psychiatric Association 2000) and/or DSM-5 ASD, with or without comorbid PD (traits), and with or without a primary diagnosis of DSM-IV and/or DSM-5 PD, and when being an adult male. Inclusion criteria for the PD group were a primary diagnosis of DSM-IV PD and/or DSM-5 PD, no past or current ASD suspicion by health care professionals, and no diagnosis of DSM-IV/DSM-5 ASD in the client charts, and being adult male.

Inclusion criteria for the general population group were not being a mental health care client, no ASD and no PD diagnosis, and being adult male. All participants had to be allocated into a typical/atypical SIS subgroup by the study psychologists based on direct observation during assessment. Written informed consent was obtained from all participants.

Exclusion criteria for all participants were female sex, and presence of current suicidal ideation, imminent danger/prominent suicidal ideation or high risk of suicide (assessed by questioning thoughts, plans, and past attempts).

5.3.3 Measures

Social interaction style

Four descriptions of the atypical SISs and one typical SIS option were made, determined by the first author after discussion with the other authors and finally approved by all authors: (1) *Active-but-odd* - The person seeks interaction with the other person (easily), but these interactions are considered strange, naive, one-sided, repetitive, or unusual. For example, the person seems unable to adapt the conversation topics or behavior to the other person, and continues to pursue his/her own topic, even if discouraged actively by the other person; (2) *Passive* - The person engages the other person, responds to contact as long as the other person initiates the interaction. The person seems to lack initiating social interaction spontaneously, only responds to questions and remarks of the other person. The communication lasts as long as the other person structures or leads the interaction; (3) *Aloof* - The person does not or hardly react when being approached, and barely talks or with obvious anomalies, such as echolalia. The person reacts hardly or not at all to gestures of the other person. Approaches are often perceived as instrumental like pulling along the other person to obtain what he/she wants or needs; (4) *Stilted* - The person intellectualizes contact with the other person, and seems to lack the intuition necessary to understand the subtleties of interpersonal contact. The person is conceived as long-winded and is considered to have a pedantic, pompous or too 'neat' style of speaking; (5) *Typical* - None of the above descriptions apply to the person. The social interaction of the person as perceived by the other person is qualified as adequate.

These descriptions were derived from *Wing's Subgrouping Scheme* (Wing & Gould 1979) and based on the SIS descriptions of the *Wing Subgroups Questionnaire* (WSQ; Castelloe & Dawson 1993), a valid and reliable parent or teacher questionnaire to determine the SIS of a child with ASD (Castelloe & Dawson 1993; O'Brien 1996). However, the WSQ has not been designed for adults and, as far as we know, has not been used in adult samples. The four descriptions are specifically focusing on adults by constructing them in line with the neurotypical social expectations within adulthood. In the present study two health care professionals experienced in

ASD classified the participants SIS by using the descriptions of the five categories. Interrater agreement of these categorizations was assessed in the data collected in the present study by Krippendorff's alpha, computed on 10,000 bootstrap replications with a minimum recommended agreement of 0.667 (Hayes & Krippendorff 2007; Krippendorff 2012). We used Krippendorff's alpha (Hayes & Krippendorff 2007), a conservative agreement estimate for judgments made by any number of raters, and adaptable to any level of measurement (Van Krugten et al. 2019, p. 4; see also Lombard et al. 2002). The Krippendorff's alpha value was 0.93 (95% CI 0.83-1.00), indicating a strong agreement between the raters.

Personality disorders

The *Structured Clinical Interview for DSM-5 Personality Disorders* (SCID-5-PD; First et al. 2016; Dutch version: Arntz et al. 2017), the updated version of the former *Structured Clinical Interview for Axis II Personality Disorders* (SCID-II; First et al. 1997; Dutch version: Weertman et al. 2000), is a semi-structured clinical interview for assessing the 106 traits of the ten DSM-5 PDs. SCID-5 PD traits are scored positive (two points) when responses and observations meet the individual diagnostic criteria specified for each DSM-5 PD trait. PD-diagnoses as well as PD-trait scores (sum of '2' ratings) were based on these. The Italian translation of SCID-5-PD shows adequate interrater reliability (Somma et al. 2017). To date, psychometric properties of the Dutch translation of SCID-5-PD are unknown.

5.3.4 Procedure

Two psychologists classified the participants' SIS (i.e., aloof, passive, active-but-odd, stilted, typical) based on direct observation of social interaction during an assessment with NIDA (Vuijk 2016) and *Autism Diagnostic Observation Schedule - 2* (ADOS-2; Lord et al. 2012; Dutch version: De Bildt et al. 2013). After the assessment the psychologists allocated the participant into one of the five categories. Each participant was also interviewed by a third psychologist, who did not classify participants' SIS, administering the SCID-5-PD (First et al. 2016) for assessing PDs. The psychologists were blind for diagnostic group (ASD, PD or general population).

5.3.5 Statistical analysis

Statistical analyses were performed using Statistical Package for the Social Sciences version 25 (SPSS Version 25, IBM, New York, NY, USA). First, descriptive statistics were used to analyze participants' demographic data. Distribution of the SIS classifications over the groups are based on the ratings of the two independent SIS assessors which were averaged. We, therefore, analyzed the distributions with a Mann-Whitney U test: the assessors' individual scores could range from 0 (both raters scored absence), via 0.5 (one rater scored absence, the other presence), to 1

(both raters scored presence). We used the exact procedure as it is valid in case of ties (Bergmann et al. 2000). Second, Spearman correlation coefficients were used to calculate the correlations between SISs and DSM-5 PD traits based on the SCID-5-PD scoring, as well as between SISs and level of education and having a relationship. A guideline by Cohen (1988) characterizes Spearman's r_s 0.50 as large, 0.30 as medium, and 0.10 as small. For both analyses a p -value of < 0.05 was considered statistically significant.

5.4 Results

5.4.1 Sample characteristics

A total of 90 participants were included: 30 ASD participants (20% AD, 33% AS, 47% ASD; 60% comorbid PD; 100% Caucasian; M age = 43.23, SD age = 11.00; 77% unmarried, 23% married; education ranged from 23% university to 3% elementary school), 30 PD participants (100% Caucasian; M age = 44.13, SD age = 12.64; 63% unmarried, 4% married, 20% divorced, 3% other; education ranged from 10% university to 7% elementary school, 3% unknown), and 30 general population participants (100% Caucasian; M age = 44.37, SD age = 14.85; 60% unmarried, 30% married, 0% divorced, 10% other; education ranged from 33% university to 0% elementary school, 3% unknown).

PD not otherwise specified (PDNOS) was most commonly diagnosed among the ASD and PD participants ($n = 27$; 45%), followed by obsessive-compulsive PD ($n = 9$; 15%) and avoidant PD ($n = 8$; 13%). In the ASD group, a total number of 18 PDs was diagnosed, with PDNOS as most common ($n = 12$; 40%), followed by obsessive-compulsive PD ($n = 5$; 17%) and schizoid PD ($n = 3$; 10%). In the PD group, a total number of 23 PDs was diagnosed, with PDNOS as most common ($n = 15$; 50%), followed by avoidant PD ($n = 7$; 23%) and borderline PD ($n = 5$; 17%). Seven out of 30 PD participants no longer met the criteria for a (specified) PD. Based on the detailed information provided in their client charts, we decided to still include these participants in the PD group given their general and long-term patterns of personality pathology.

For a full and more detailed description of the demographic characteristics of the participants, we refer to Table 1 from Vuijk et al. (2021) and Table 2.1 from Chapter 2.

5.4.2 Distribution of the SISs over the groups

Table 5.1 presents the distribution of the SIS classifications over the three groups. There were no participants allocated to the aloof SIS. ASD participants were distributed over the atypical SISs (active-but-odd, passive, stilted) as well as the

typical SIS. Participants of the PD group were only allocated to the active-but-odd SIS or the typical SIS. All general population participants were allocated to the typical SIS.

We observed a significant difference in allocation to the active-but-odd and the passive SISs in the ASD group between the ASD without PD and the ASD with PD participants ($U = 62, p = .023 / U = 66, p = .015$). The ASD without PD participants were more allocated to the active-but-odd SIS and not at all to the passive SIS compared to the ASD with PD participants. The difference in allocation to the stilted SIS and the typical SIS between the ASD without PD and the ASD with PD participants was not significant ($U = 102, p = .78 / U = 94, p = .36$).

We observed a significant difference in allocation to the passive, stilted, and typical SISs between the ASD group with and without PD and the PD group ($U = 285 / U = 326.5 / U = 157.5; p's = < .001$). As to the ASD-PD comparison, the ASD group received higher passive and stilted SISs scores than the PD group, whereas the typical SIS scores were higher in the PD group compared to the ASD group. The difference in allocation to the active-but-odd SIS between the ASD and PD groups was not significant ($U = 388, p = .33$).

We observed a significant difference in allocation to the passive, stilted, and typical SISs between the ASD group with PD and the PD group ($U = 165, p = < .001 / U = 202, p = .012 / U = 104, p = < .001$). The ASD with PD participants were more allocated to the passive and stilted SISs compared to the PD participants. The ASD with PD participants were less allocated to the typical SIS. The difference in allocation to the active-but-odd SIS between the ASD with PD and the PD participants was not significant ($U = 260, p = .78$).

We observed a significant difference in allocation to the active-but-odd, passive, stilted, and typical SISs between the ASD and the general population group ($U = 270 / U = 285 / U = 315 / U = 45; p's = < .001$). As aforementioned, all general population participants were allocated to the typical SIS (30 of 30).

Table 5.1 Distribution of the averaged SIS classifications over the ASD ($n = 30$), PD ($n = 30$), and COM ($n = 30$) groups

	Active-but-odd SIS			Passive SIS			Stilted SIS			Typical SIS		
	<i>n</i> (%)	Mean	SD	<i>n</i> (%)	Mean	SD	<i>n</i> (%)	Mean	SD	<i>n</i> (%)	Mean	SD
ASD group	11.5 (38)	.38	.49	7 (23)	.23	.46	8 (27)	.27	.43	3.5 (12)	.12	.31
ASD without PD	7.5 (25)	.63	.48	0 (0)	.00	.00	3.5 (12)	.29	.45	1 (3)	.08	.29
ASD with PD	4 (13)	.22	.43	7 (23)	.39	.50	4.5 (15)	.25	.43	2.5 (8)	.17	.34
PD group	7.5 (25)	.25	.43	0 (0)	.00	.00	0.5 (2)	.02	.09	22 (73)	.73	.43
COM group	0	0	0	0	0	0	0	0	0	30 (100)	1.00	0
Total ASD, PD and Com groups	19 (21)	.21	.40	7 (11)	.11	.31	8.5 (9)	.09	.28	55.5 (61)	.62	.48
ASD without PD vs ASD with PD						.023					.772	
ASD group vs PD group						.328					.004	
ASD with PD vs PD group						.777					.012	
ASD group vs COM group						<.001					<.001	

ASD = Autism spectrum disorder; COM = General population comparison group; PD = Personality disorder; SIS = (a)typical social interaction styles defined specifically for adults in the current study.
 Note: Distributions of the SIS classifications are based on the average scores of two independent raters. In five cases they classified participants differently. In these cases, the participants received a 0.5 score on the SIS.
 Note: *p* = exact significance (2-tailed).

5.4.3 Correlations between SISs and DSM-5 PD traits

Table 5.2 presents the correlations of the DSM-5 PD traits assessed with SCID-5-PD per PD for the (a)typical SISs. Spearman correlation analysis yielded negative significant associations between the active-but-odd SIS and the schizoid PD traits ($\rho = -0.27, p = 0.035$), and between the stilted SIS and dependent PD traits ($\rho = -0.28, p = 0.034$), as well as the borderline PD traits ($\rho = -0.30, p = 0.019$) demonstrating medium associations. Spearman correlation analysis yielded positive significant associations between the typical SIS and the histrionic, borderline, and antisocial PD traits ($\rho = 0.40, p = 0.002$; $\rho = 0.37, p = 0.003$; $\rho = 0.29, p = 0.025$) demonstrating also medium associations.

We additionally calculated Spearman's ρ for the SISs, level of education, and having a relationship. Spearman correlation analysis yielded a significant negative association between the active-but-odd SIS and level of education ($\rho = -0.29, p = 0.025$), and a significant positive association between the stilted SIS and level of education ($\rho = 0.32, p = 0.014$), demonstrating medium associations. No significant associations were found for SISs and having a relationship.

Table 5.2 Spearman correlations between SISs and DSM-5 PD traits ($N = 60$)

	Active-but-odd SIS		Passive SIS		Stilted SIS		Typical SIS	
	ρ	<i>p</i>	ρ	<i>p</i>	ρ	<i>p</i>	ρ	<i>p</i>
Avoidant-PD	-.06	.662	.06	.660	-.23	.076	.15	.248
Dependent-PD	-.02	.854	-.03	.797	-.28	.034†	.24	.069
Obsessive-compulsive-PD	-.10	.471	-.01	.936	-.01	.968	.08	.558
Paranoid-PD	-.07	.621	-.07	.575	.03	.818	.16	.218
Schizoid-PD	-.27	.035†	.21	.100	.12	.345	-.07	.573
Schizotypal-PD	.07	.612	.08	.527	-.21	.101	.04	.751
Narcissistic-PD	-.02	.868	.12	.369	-.13	.312	.12	.360
Histrionic-PD	-.10	.456	-.18	.168	-.12	.352	.40	.002†
Borderline-PD	-.03	.850	-.25	.053	-.30	.019†	.37	.003†
Antisocial-PD	-.17	.191	-.11	.413	-.06	.648	.29	.025†

PD = Personality disorder; SIS = Social interaction style

† Correlation is significant at the 0.05 level (2-tailed)

Note: DSM-5 PD traits are based on the SCID-5-PD assessment.

5.5 Discussion

As subtypes of atypical SISs, for the first time described by Wing and Gould (1979) has been studied only in children and adolescents with ASD as far as we know, this study explored the subtypes of atypical SISs in adults with ASD. We aimed to explore the SISs of adult males with ASD and with or without PD (traits) compared to males with PD without ASD, and males without ASD and without PD. We further explored the relationship between (a)typical SISs and DSM-5 PD traits assessed with SCID-5-PD, and between (a)typical SISs and level of education, and having a relationship.

Our findings demonstrate a clear distinction in distribution of (a)typical SISs between the ASD group and the PD group (88% vs 27%), and between the ASD group and the general population group (88% vs 0%). All atypical SISs were more allocated to the ASD group than to the PD group whereas the typical style was represented more often in the PD group, and it was the sole SIS represented in the general population group. As expected, as social interaction challenges are a key indicator of ASD, the manifestation of atypicalities in SIS is far more characteristic of individuals with ASD than of individuals with PD. In previous studies, the active-but-odd SIS has been associated with lower ASD severity rates compared to the aloof and passive SISs (Roeyers 1997; Scheeren et al. 2020; Waterhouse et al. 1996). This might be one of the reasons that if participants from the PD-group were allocated to a SIS category, it was almost always to the active-but-odd SIS: all PD individuals in our study had no past or current suspicion on ASD. This explanation contradicts with what we observed when dividing those with an ASD in meeting criteria for a PD or not, as the active-but-odd SIS seemed more common in those with ASD without PD. We have no explanation for this difference, and believe that given the small sample sizes in this subdivision replication of this finding is first needed before speculating what this difference entails.

As overall classification of atypical SISs and the number of DSM-5 PD traits are low, our correlational findings must be interpreted with caution. Our results hint at the lack of associations between (a)typical SISs and DSM-5 PD traits. The exceptions were: 1) the active-but-odd SIS was negatively associated with schizoid PD traits, and 2) the stilted SIS was negatively associated with dependent and borderline PD traits. One can imagine that the schizoid lack of interest in social interaction, and shying away from others are not associated with the active-but-odd SIS of (easily) seeking interaction with others. Moreover, one can imagine that the borderline unstable interpersonal relationships and strong emotionality are not associated with the stilted formal and strict way of behaving and living. Last but not least, it also seems plausible that the intellectual, long-winded, and pedantic conception of stilted SIS individuals is not associated with the dependent PD tendency of lacking confidence and placing needs and opinions of others above their own. SISs might be related to educational level as having an active-but-odd SIS was associated with relatively lower educational levels, while having a stilted SIS is associated

with higher educational levels. The lower educational levels for the active-but-odd SIS appear to correspond to a study examining the psychometric properties of the WSQ (Wing & Gould 1979) finding the lowest IQ scores for the active-but-odd SIS compared to the passive and aloof SISs in children with ASD. It does make sense that as the stilted SIS has a profile of intellectualizing in contact and speaking is indeed related to the more higher 'verbal' than lower 'practical' educational levels.

The key strengths of this study are the broad age range of the participants, and the descriptions of the SISs focused on adults showing a strong interrater agreement. Further, our findings may complement the previous findings on atypical SISs in children and adolescents with ASD (Beadle-Brown et al. 2002; Scheeren et al. 2020) by investigating adults with ASD. When we compare the distribution of SIS classifications over the ASD group with the results reported in a 4-year follow-up study (Scheeren et al. 2020) examining longitudinal stability and change of SIS in children and adolescents with ASD (n = 55; mean age Time 1: 13 years; mean age Time 2: 17 years), we see: (1) their allocation to the passive SIS (T1: 18%; T2: 20%) and the active-but-odd SIS (T1: 47%; T2: 33%) were more or less comparable to our findings of 23% passive SIS and 38% active-but-odd SIS, (2) the typical style was far more allocated in their study (T1: 33%; T2: 44%) compared to our study (12%), and (3) the aloof SIS was represented and the stilted SIS was not represented in their study: in our study it was the other way around. More or less comparable percentages for the active-but-odd and passive SISs in both studies may suggest a stability of these behavioral features over time: a longitudinal cross-sectional research including both youth and adults with ASD is needed. A 4-year follow-up study of stability and change of SIS of children with ASD already suggested SIS being part of children's temperamental tendencies (Scheeren et al. 2020). Future research must shed light on (a)typical SISs being part of temperament, which is part of the concept of personality: are (a)typical SISs and personality (pathology) conceptually and etiologically mutually exclusive or overlapping? In line with this, we can imagine to study and possibly discuss whether or not we should mention ASD as exclusion criterion under schizoid as well as schizotypal PDs in the DSM-5. In the introduction, we discussed the usefulness of knowing an individual's atypical SIS as well as his/her personality (pathology). We also consider it to be advantageous to have knowledge about both SIS and PD in an adult with ASD. For specific PDs special therapeutic approaches have been described for building and developing a good therapeutic alliance (Bender 2005). Schema therapy (ST), for instance, effective for treating PDs (Bamelis et al. 2014; Sempérteguia et al. 2013; Videler et al. 2018), provides the therapist different strategies for establishing and maintaining a working relationship by considering the specific needs of each PD (Young et al. 2003). When a specific atypical SIS is correlated with a specific PD, the interaction strategy for the specific PD may be useful for a therapist treating an individual with ASD with an atypical SIS. With

the preliminary correlational findings of this initial and exploratory study, future studies must include a broader sample of atypical SISs as well as PDs and PD traits to discover any relationship between atypical SISs and PDs. Future studies are also welcome with a more heterogeneous constitution of the ASD sample when it comes to sex, gender, and comorbid PD-pathology to better understand the trajectory of the development of atypical SISs in males as well as females with ASD and how this impacts diagnosis received in later adolescence or adulthood.

This study is not without limitations. First, we only included males. As we know the phenotypic differences between males and females with ASD (Loomes et al. 2017; Wilson et al. 2016), the inclusion of males with ASD only limits the generalizability of the findings to females with ASD. Second, the males with ASD were all (ex-)clients of a mental health institute limiting the generalizability of the findings to all males with ASD. As the males we selected for the ASD and PD groups were recruited at the end of their treatment or already dismissed from treatment, this could well have resulted in the observed lower prevalence of PDs compared to what is to be expected from clients with ASD and/or PD when referred for diagnosis and treatment. Third, the lack of valid and reliable ways of subtyping and measures related to social interaction or social communication (Agelink van Rentegeem et al. 2021) is a significant limitation. Finally, subgrouping can lead to misperceptions and stigma in society: We thus explicitly emphasize that our findings are especially relevant in a therapeutic context, clarifying the differences and heterogeneity amongst individuals with ASD without intending creating new categories. Regarding misperceptions and stigma, typically developing (TD) adults express less interest in interaction with partners with ASD relative to TD partners (Morrison et al. 2020). Besides, adults with ASD express greater inclusivity and less discriminatory attitudes about social differences among each other compared to TD adults (DeBrabander et al. 2019).

In conclusion, this study shows the presence of atypical SISs in adult males with ASD, and complements previous atypical SIS findings in children and adolescents with ASD. The current findings suggest the atypical SISs are more common in the ASD than the PD group as well as the general population group. Our study may contribute to a better understanding of individual differences in adult male clients with ASD taking atypical SIS into account might be potentially beneficial in improving (therapeutic) relationships. However, a first future research avenue is to determine the stability over time and context of these SISs and the relationship with PDs.

Part III

Psychotherapy



6

Schema Therapy for adults with autism spectrum disorder and comorbid personality disorder: A case example

Richard Vuijk, Hannie van Genderen, Hilde M. Geurts, Arnoud Arntz

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Abstract

This chapter outlines Schema Therapy (ST) as a treatment possibility for adults with autism spectrum disorder (ASD) and comorbid personality disorder (PD). ST is introduced, followed by a summary of empirical findings about personality characteristics in people with ASD including both weaknesses (i.e., pathology) and strengths. A summary is provided of the empirical studies examining ST concepts and treatment programs for adults with ASD (and comorbid PD). The chapter concludes with a case study exemplifying the ST approach.

Author contributions

All authors contributed to the conception and design. Hannie van Genderen drafted the introduction. Richard Vuijk drafted the manuscript with critical input from the other authors. All authors read and approved the final manuscript.

6.1 Introduction to Schema Therapy

Schema Therapy (ST) is an innovative, integrative therapeutic approach originally developed by Jeffrey Young as an extension of traditional cognitive behavioral treatments (Young et al. 2003). The schema approach draws from cognitive behavioral therapy (CBT), attachment theory, psychodynamic concepts, and emotion-focused therapies. ST is particularly well-suited and effective for people with chronic mental disorders, including personality disorders (PDs), eating disorders, and chronic depression (Bamelis et al. 2014; Renner et al. 2013; Sempérteguia et al. 2013; Simpson et al. 2010).

A central tenet of ST, drawn from CBT, is that everyone develops schemas during childhood. A schema is an organized knowledge structure that develops in early life and manifests in certain behaviors, feelings, and thoughts. Dysfunctional schemas (such as social alienation, social undesirability, failure, hypercriticalness, subjugation) develop when some core emotional needs (safety, acceptance, nurturance, autonomy, self-appreciation, self-expression, and realistic limits) are not met during formative years. This may be due to shortcomings in the child's environment, or in combination with traumatic events (such as emotional, physical, or sexual abuse, or being bullied) in interaction with the child's temperament. A coping response in combination with a schema results in a so-called schema mode, which describes the momentary emotional-cognitive-behavioral state of the person. A schema mode (such as vulnerable child, happy child, compliant surrender, detached self-soother, demanding parent) is a set of schemas and processes, which, in certain situations, determine the thoughts, feelings, and actions of the person.

ST focuses on changing dysfunctional schemas and maladaptive modes into more flexible and less extreme schemas/modes, and developing adequate coping strategies so that clients develop a more positive image of themselves and others, as well as a more nuanced view of the world around them. First, the therapist and client create a case conceptualization based upon the schemas and modes. Next, in the treatment phase, therapists make use of experiential, cognitive, and behavioral techniques, influencing the client through three channels: feeling (experiential), thinking (cognitive), and doing (behavioral). The experiential techniques (including imagery rescripting, chair work dialogue, historical roleplay) seem to be the most crucial mechanisms of change, as they appear to change the schemas and modes on an emotional, as well as cognitive level. The application of ST techniques can only be successful once a certain level of trust and attachment to the therapist is formed. The therapeutic relationship can be described as limited reparenting, whereby the therapist goes into this relationship as if they are a parent figure for the client.

6.2 Autism spectrum disorder: Personality weaknesses and strengths

An increasing number of studies have examined autism spectrum disorder (ASD) and comorbid personality pathology. A literature review by Vuijk et al. (2018; see Chapter 3) showed strong indications for personality pathology in adults with ASD, such that ASD appeared to be significantly associated with several temperament and character dimensions, and with major PDs. Some adults with ASD, for example, were found to have an introverted, rigid, and passive-dependent temperament and a risk for deficits in character development with low self-directedness and cooperativeness. The majority of adults with ASD do not have a co-occurring PD, but prevalence of PD appears to be higher than in neurotypical adults. The prevalence of meeting criteria for a PD ranges from 48% to 62% among adults with ASD drawn from clinical samples (Hofvander et al. 2009; Lugnegård et al. 2012). Results of a meta-analysis (Vuijk et al. 2018; see Chapter 3) indicated that the most common PDs were paranoid (24%), schizoid (24%), schizotypal (14%), avoidant (23%), and obsessive-compulsive (32%). To summarize, there is a strong association between ASD and dysfunctional personality traits, as well as between ASD and PD, specifically cluster A (paranoid, schizoid, schizotypal) and cluster C (avoidant, dependent, obsessive-compulsive) PDs.

Both ASD and personality disorder (PD) are associated with a long-term pattern of difficulties in interpersonal functioning. ASD is characterized by persistent problems in social communication and social interaction; in other words, a persistent social disability or a neurodevelopmental condition with a focus on problems in the social domain. PD is not characterized by a persistent social disability, but by interpersonal difficulties, based on a combination of temperament difficulties and early problematic relationships with others, attachment pathology and/or stressful situations or events. Each of the DSM-5 PDs (American Psychiatric Association 2013) describes particular types of interpersonal difficulties. For example, when having an avoidant PD, contact is disturbed by feelings of inadequacy and hypersensitivity to being negatively evaluated. In our case study we will meet Christian, diagnosed with ASD (in his childhood) and in adult life with comorbid avoidant PD traits: for him, ASD means a challenge and difficulty in interpreting verbal and nonverbal communication, reading other people's emotions, and expressing his own emotions. In his childhood his parents and his peers did not always know how to deal with his ASD. In childhood, negative reactions of others were a real burden and a serious cause of stress for him: he developed low self-esteem and a pattern of fear of being negatively evaluated. The combination of the negative reactions and his thoughts and feelings shaped his personality in an avoidant way.

Importantly, research shows that ASD is also associated with positive personality attributes. In a study examining character strengths in adults with ASD, intellectual open-mindedness (i.e., thinking things through, examining aspects from all sides), authenticity, love of learning, creativity, and fairness were found to be the most frequent signature strengths (Kirchner et al. 2016).

6.3 ASD and Schema Therapy

People with ASD may have a vulnerability to maladaptive schema development, partly because of their different ways of processing information about others, the self, and nonsocial information, often resulting in social difficulties as well as difficulties with self-management (Gaus 2019). For example, children with ASD might be at risk of being misunderstood, excluded, and maltreated because of their ASD and/or the impact of symptoms. Such early experiences are well-known risk factors for deficits in character development and the development of PDs. Adults with ASD have scored significantly higher on all the early dysfunctional schemas, apart from self-sacrifice and approval/recognition seeking, compared to typically developing adults (Oshima et al. 2015). Early dysfunctional schemas have also appeared to account for poorer general mental health in nonclinical adults with autism spectrum traits (Oshima et al. 2014).

The increased recognition of personality pathology in adults with ASD implies the need for interventions for personality pathology in this population. To date, very few studies have examined the acceptability and effectiveness of psychosocial interventions for PD in adults with ASD. A naturalistic multiple case study ($N=8$, aged 20 to 35, four males, four females) indicated that individual ST is applicable as a treatment for adults with ASD and comorbid psychiatric conditions narratively showing positive changes in quality of life, symptoms of ASD, cognitive schemas, and schema modes (Oshima et al. 2018). However, a lack of specific details and limited documentation of methodology and statistical analysis renders this study difficult to interpret the positive changes. A specific ST program for adults with ASD and comorbid PDs has been developed and investigated by Vuijk and Arntz (2017; see Chapter 7). As far as we know, this is the first study investigating ST in adults with ASD and comorbid PD(s). Results of this study are promising, showing a significant decrease of dysfunctional core beliefs, PD traits, psychopathological symptoms, an increase of the functional schema mode of Happy Child, and an improvement in social responsiveness. These results are expected to be published in 2022 (see Chapter 8).

For several reasons, ST might be a useful therapy for adults with ASD and comorbid PD (see also Vuijk & Arntz 2017; Chapter 7). First, there is increasing empirical support for this therapy as a valuable treatment for PDs, as described in the beginning of this chapter. Second, the therapeutic relationship is active, consistent, supportive, and directive with regard to both content and process, which we consider helpful for people with ASD who are more often characterized by low self-directedness as compared to the general population. Third, ST is a structured and focused psychotherapy, suitable for people with ASD, who often seem to benefit from this way of working. Thus, the approach common in ST (i.e., step by step, focused on a theme, structured by explanation and psychoeducation, and goal-directed) is likely to be of use for people with ASD. A *Schema Therapy Modified for Autism Spectrum Conditions* (ST-MASC) was developed by Bulluss (2019). This model provides a framework and an extension of the regular ST elements in which autism-driven coping responses and autism-specific needs are incorporated and conceptualized. The model provides illustrative examples of how some people with ASD cope with their core autistic features living in a neurotypical world, using ST terms originally developed to describe how people can dysfunctionally cope with maladaptive schema activation: by surrendering, overcompensating, or avoiding. This can be understood in terms of eye contact, for example: (a) the coping response of surrendering for the tendency of limited eye contact is, for instance, staring at the floor or past people, (b) the coping response of overcompensating is focussing too much on making eye contact or staring at times, and (c) an avoidant coping response is avoiding situations involving face to face interaction, resulting in isolation. Autism-specific needs are, for instance, the freedom to focus on interests and a stable and reliable base for routine, predictability, and sameness.

6.4 Schema Therapy for people with ASD: Clinical considerations

When starting ST, there are some ‘dos and don’ts’ for a therapist treating PD in people with ASD:

- As a therapist, first take care to set clear expectations about the role of the therapist and the client, setting a realistic pace, using language effectively, validating the client’s experience, and providing constructive feedback (Gaus 2019).
- At the beginning of every ST session review psychoeducation of the ST concepts and the specific interventions in order to set clear expectations for clients with ASD. After an intervention, it is helpful to explain or discuss in detail what has been done and what it means for the client’s here-and-now situation.

- When cognitive restructuring dysfunctional core beliefs or schema modes, post-its (at the wall or in the chair when doing chair dialogues) can make beliefs or modes more visible and concrete in the here-and-now for clients with ASD.
- People with ASD often say they have never had the opportunity to explore difficult and challenging personal situations and getting constructive feedback on their thoughts and feelings. A man with ASD, avoidant PD, and traumatic memories caused by being bullied for 10 years in his childhood by other children was treated with ST: his reaction after imagery rescripting sessions was that the trauma had been solved because he had verbalized the trauma in therapy. For him, the trauma was easier to deal with in his daily life.
- For people with ASD, experiential interventions can be a challenge. For example, a woman with ASD and obsessive-compulsive PD could not imagine herself as a child. The therapist solved this as follows: he let her imagine a general family situation at a dinner table with a father, a mother, and a little child. After the intervention she discovered that in the imagery rescripting she had brought up her own family situation and she was the little child. Explaining, translating, and discussing afterwards can lead to expression of new functional beliefs about one’s self. Another example is a man with ASD and schizoid PD who said when starting imagery rescripting, ‘I do not feel, but I think. I have a clear and detailed picture how it used to be when I was a child: I do have no feelings, but only thoughts about it.’ The therapist can validate the client’s attempt to imagine: he did it in a cognitive way. He finally expressed new functional core beliefs (of the past) and could change his actual situation by improved cognitive mentalizing.

ST does not differ substantially for people with ASD compared to people with other mental disorders. ‘The psychotherapist needs to be fluent in “Aspergerese”; in other words, to recognize that autism is a different way of thinking – almost a different culture – and be able to translate the concepts and components of the therapy to someone with this different way of thinking’ (Gaus 2019, p. ix). Taking into account the ‘dos and don’ts’, the autism-specific needs and challenges, as well factoring in personality strengths, we believe ST can be a potential effective treatment for PD in people with ASD.

6.5 Case study: Christian

6.5.1 Demographic information

Living situation

Christian is a 52-year-old Dutch man. He lives alone, has no partner and no children. He worked for 23 years as a high school teacher in mathematics. Last year, he was dismissed: he was unable to deal with the major changes in the Dutch system for high school education. Currently, he works as a volunteer in a group home for elderly people one day a week, serving coffee and tea.

Christian is a member of a Dutch network for, and led by, adults with ASD, visiting its activities once a month. Further, he spends a lot of time home alone.

History

Christian is an only child. His father worked as a teacher in Latin language at high school. His mother was a nurse in a children's hospital. After high school Christian obtained his Master's degree in Mathematics at university.

During childhood, there was a lot of order and discipline at home. He experienced challenges in understanding others and playing with other children. His parents did not encourage him to join other children, so he seldom dared to participate: as a child, he felt afraid of his peers' negative reactions toward him, which he considered were due to him not knowing how to interact with them. He had a strong desire for interaction, but did not feel that he possessed the knowledge or skills to do this adeptly. In his childhood, he was a member of the Scout movement. When he participated in scouting activities, he was often a loner in the group and rarely involved in activities or plays. These experiences contributed to him feeling unlikable and unwanted, and he developed core beliefs relating to being different, not good enough, and bound to be alone. He developed a pattern of low self-esteem and avoidance of interpersonal contact, due to fear of disapproval and rejection.

6.5.2 Presenting problems

After being dismissed from his teaching post, Christian visited his general practitioner (family doctor), reporting depressed feelings and social anxiety. He was referred to a center specializing in diagnostic assessments and treatments for adults with ASD.

His key presenting difficulties were low self-esteem, a substantial need for order and interpersonal control, fear of negative evaluation, and a depressed mood. In addition, his ASD-specific challenges related to trying to understand what others meant: he often needed extra time to process what he hears, sees and feels when having contact with others.

In his manner, Christian presented as very kind. He regularly sought clarification regarding the actual meaning of remarks made by the therapist. He also asked for a clear and structured way of communicating and required time to provide what he felt was the right answer.

6.5.3 Assessment and diagnosis

Mental disorders were assessed at intake in a structured, organized, ASD-friendly way. After the assessment, his ASD was confirmed and Christian was additionally diagnosed with depressive disorder, social anxiety disorder, and avoidant PD traits. Pharmacological treatment, CBT, and ST were indicated.

6.5.4 Individualized treatment plan

Goals

First, depressive disorder and social anxiety disorder were treated with antidepressants and CBT focusing on scheduling enjoyable activities, physical exercise, relaxation skills, *in vivo* exposure and cognitive interventions. After a period of four months of treatment, ST was introduced to enhance Christian's ability to challenge dysfunctional core beliefs (schemas), coping styles, and schema modes: to increase functional coping styles and schema modes; and to help meet basic emotional needs.

Christian hoped to increase his competence and confidence in social situations, thereby feeling less anxiety and stress in these situations. He wanted to express new beliefs about himself, such as 'I am capable and competent' and 'I am good enough to be loved by others.' He also wanted emotional memories to feel less intense.

Schema Therapy

ST for Christian consisted of four phases: (a) 5 sessions exploring current and past functioning, psychological symptoms, dysfunctional core beliefs, and schema modes; (b) 15 weekly sessions of cognitive behavioral interventions; (c) 15 weekly sessions of experiential interventions; and (d) 10 monthly follow-up booster sessions.

6.5.5 Experiential interventions

Imagery rescripting and chairwork dialogues are powerful experiential techniques. Imagery rescripting uses the power of imagination and visualization to identify and change meaningful and traumatic orders in the past, resulting in transformation in the present (Wijngaart & Hayes 2016). Chairwork dialogues give a chair to the schema modes in the individual so that they can enact or re-enact scenes from the past, the present, or the future. To make these interventions more accessible for people with ASD, like Christian, the therapist takes into account the 'dos and don'ts' and the autism-specific needs and challenges mentioned in the fourth paragraph of this chapter. Here, we exemplify two experiential interventions by outlining

one of Christian's imagery rescripting sessions and chairwork dialogue sessions, helping him to bring about actual behavioral change and less intense emotions and memories. Christian described a recent situation in which he felt completely ignored by his colleague volunteers at the elderly home. At team meetings, he never felt able to say what he wanted to say, at the right time, as conversations moved on too quickly for him.

Imagery rescripting

Therapist (T): Christian, can you close your eyes and imagine the meeting from last week?

Christian (C): Yes, I am sitting in the meeting room, we are having a meeting with all 10 of the volunteers. Everyone is talking and mentioning things they want to say.

Everyone except me.

T: And what do you feel?

C: I feel frustrated.

T: Stay with that frustration for a moment. Can you feel it right now?

C: Yes, I feel it in my shoulders.

T: I want you to concentrate on that feeling. The situation with your colleagues.

Let it go. Go back to your childhood and see if a situation comes in mind in which you are also frustrated as a little child.

(Christian is thinking)

T: And do you have an image?

C: I am at scouting, and again, I am standing on the sidelines, I am not participating in building a tent and nobody asks me to join in. Even the leaders do not pay attention to me. I want to join, but I do not know how.

T: Is it okay, if I enter the image and talk to the leaders to support you?

C: Yes, that's okay.

T: *[To the leaders]* I would like you to know that little Christian is standing all alone and he wants to join. Can you please involve him in building the tent?

[To Christian] Is this okay for you, Christian?

C: Well, I am not convinced the leaders will listen to you.

T: Then, I will repeat it again and in a louder voice. *[Therapist repeats the message to the leaders with a louder voice.]*

C: Ah, that feels better. I can see that one of the leaders is coming up to me and asks me to join building the tent.

T: Okay, Christian, take a minute to enjoy the event. When you are okay with it, you may open your eyes and return to the therapy room. How do you feel?

C: This was for me the first time that someone [the therapist who came in the imagery exercise] was giving me support. It feels very good.

T: How can this exercise help you when being together with your colleagues?

C: *[Christian is thinking]* Well I think, I have to speak the manager before the meeting and ask her to give me some time to say something during the meeting.

T: That sounds good.

C: Yes, but I am not sure how I can ask her, how I have to do this.

T: Let us give it a try: we can practice this in a role play.

Chairwork dialogue

Christian was now confronted with two scenarios: "Do I still say nothing at team meetings or do I say what I want to say?" He felt very nervous thinking about this dilemma, having a voice in his mind telling him he would not succeed. The therapist invited him to a three-chair dialogue to give voice to what he was currently feeling and experiencing. In one chair he gave voice to his vulnerable child mode ("I feel ashamed of myself when starting conversation in a group"), in the second chair he gave voice to his demanding parent mode ("You will not succeed"), and in the third chair he gave voice to his healthy adult mode ("I know you find this scary, because you are not used to saying what you want to say at team meetings, but I know you will succeed. It is ok if you don't speak in perfect sentences. It is much more important that you speak up than that you strive for perfection, because then you are much more likely to say nothing").

The therapist guided him through the dialogue by asking him to take place vice-versa in the chairs, especially repeating and strengthening the functional words and thoughts that came up in Christian's mind. Christian switched several times from chairs, having a dialogue between his shame and social anxiety (vulnerable child mode), his highest standards and self-criticism (demanding parent mode), and his growing assertiveness and self-confidence (healthy adult mode), in the end resulting in less tense feelings and more realistic and confident thoughts about himself regarding the team meetings.

6.5.6 Evaluation of treatment

At follow-up Christian reported that he found ST a long and intensive treatment. During the therapy, he often wondered if all the interventions and the talking could glean a positive outcome. ST was confronting, yet in the end, he realized that it brought him new functional core beliefs about himself (such as “I am different, but I am good enough the way I am”; “I am confident enough in saying what I want to say”), better self-esteem, less anxious feelings and thoughts, and more skills to manage social interaction.

6.6 Conclusion

We believe ST might be a potential treatment for PD in people with ASD, when also taking into account the autism-specific needs and challenges and making use of the personality strengths. Randomized effectiveness studies are needed. Promising results of a first study examining ST in people with ASD and comorbid PD are expected in the near future (see Chapters 7 and 8).

7

Schema Therapy as treatment for adults with autism spectrum disorder and comorbid personality disorder: Protocol of a multiple-baseline case series study testing cognitive behavioral and experiential interventions

Richard Vuijk, Arnoud Arntz

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Abstract

To our knowledge, treatment of personality disorder (PD) comorbidity in adults with ASD is understudied, and is still in its infancy. This study investigates the effectiveness of Schema Therapy (ST) for PD psychopathology in adults with both ASD and PD. Twelve adult individuals (age > 18 years) with ASD and at least one PD are given a treatment protocol consisting of 30 weekly offered sessions. A concurrent multiple baseline design is used with baseline varying from four to nine weeks, after which weekly supportive sessions varying from one to six weeks start with the study therapist. After baseline and one to six supportive sessions, a five-week exploration phase follows with weekly sessions during which current and past functioning, psychological symptoms, and schema modes are explored, and information about the treatment is given. This is followed by 15 weekly sessions with cognitive behavioral interventions and 15 weekly sessions with experiential interventions: participants are vice versa and randomly assigned to the interventions. Finally, there is a 10-month follow-up phase with monthly booster sessions. Participants are randomly assigned to baseline length, and report weekly during treatment and monthly at follow-up on Belief Strength of dysfunctional core beliefs, and fill out SMI, SCL-90 and SRS-A seven times during screening procedure (i.e., before baseline), after supportive sessions, after exploration, after cognitive and behavioral interventions, after experiential interventions, and after 5- and 10- month follow-up. The SCID-II is administered during screening procedure, and at 5- and at 10-month follow-up.

Author contributions

Richard Vuijk and Arnoud Arntz designed the study. Richard Vuijk drafted the majority of the manuscript with critical input from the other author. Richard Vuijk obtained funding for developing SPSS database. Both authors read and approved the final manuscript.

7.1 Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with an early childhood onset and symptoms that persist throughout one's lifetime. In DSM-IV (American Psychiatric Association 2000) and in DSM-5 (American Psychiatric Association 2013) ASD is described on a behavioral level only. In DSM-IV the core symptoms are qualitative impairments in social interaction, qualitative impairments in communication, and restricted repetitive and stereotyped patterns of behavior. In DSM-5 the core symptoms are persistent deficits in social communication and social interaction across multiple contexts, and restricted, repetitive patterns of behavior, interests, or activities. The social disability is multifaceted with deficits in social-emotional reciprocity, in social non-verbal communication, and in developing, understanding, and maintaining relationships.

Both clinical practice and epidemiological research show that more than 70% of individuals with ASD have concurrent and impairing medical, developmental, or psychiatric conditions (like anxiety disorders, mood disorders, and personality disorders (PDs)) (Croen et al. 2015; Lai et al. 2014; Mannion & Leader 2013; Tebartz Van Elst et al. 2013). As people with ASD become more aware of their limitations, the risk of developing these comorbidities increases. The prevalence of these disorders is significantly higher in high functioning people with ASD than in neurotypical adults (Lugnegård et al. 2011; Skokauskas & Gallagher 2010; Hofvander et al. 2009). In a study investigating the connections between ASD and PSs, approximately 50% of adults with ASD fulfilled criteria for a PD (Lugnegård et al. 2012). Four studies (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002; Vuijk et al. 2012) found low scores on the character dimensions Self-Directedness and Cooperativeness, indicating personality pathology (Cloninger 2000). The high prevalence of mental health comorbidity and the negative impact of comorbidity on outcome and general functioning in society make treatment necessary (Renty & Roeyers 2006).

The field of treatment research for adults with ASD is still in its infancy, and in the literature autism and psychotherapy are rarely combined, but it does not seem an impossible combination (Vermeulen & Vanspranghe 2006). The focus of therapy must be the specific need of the individual with ASD whereby ASD can be seen as a basic persistent and pervasive disorder on which comorbid mental disorders secondarily arise. Few treatment options are available so far, and the effectiveness of existing treatment interventions for adults with ASD with and without comorbid mental disorders, such as cognitive behavioral therapy (CBT) and pharmacological therapies, remains very limited, and has yet to be demonstrated with scant though promising results (Binney & Blainey 2013; Bishop-Fitzpatrick et al. 2013; Cachia et al. 2016; Eack et al. 2013; Gantman et al. 2012; Howlin 2014; Leclerc & Easley 2015; Spain & Blainey 2015; Spain et al. 2015).

We have, therefore, developed a specific Schema Therapy (ST) program for adults with ASD and comorbid PD(s). We settled on ST for several reasons. First, there is more and more evidence-based support for this therapy as a valuable treatment for PDs (Bamelis et al. 2014). Second, the therapeutic relationship is active, consistent, supportive, and directive with regard to both content and process, which we consider helpful for people with ASD who are characterized by low Self-Directedness (Anckarsäter et al. 2006; Sizoo et al. 2009; Sizoo et al. 2014; Söderström et al. 2002; Vuijk et al. 2012). Third, ST is a structured and focused psychotherapy, which we consider to be suitable for people with ASD who benefit from structure and focus. The program consists of both cognitive behavioral and experiential interventions. Cognitive behavioral interventions are focused, structured, and goal-directed, and thus suitable with a view to the nature of the disorders in ASD and the associated need for clarity and structure. We apply the same approach to our experiential interventions: step by step, focused on a theme, structured by explanation and psycho-education, and goal-directed.

7.2 The present study

The aim of the study is to investigate whether ST with cognitive behavioral and experiential interventions will be effective for adults with ASD and at least one PD. The research question is: 'Can adults with comorbid ASD-PD benefit from ST, more specifically its cognitive behavioral and experiential interventions?'

The first objective is to study in detail the effects of the major technique groups of schema therapy - that is, the cognitive behavioral techniques and experiential techniques - on belief strength of dysfunctional core beliefs in adults with comorbid ASD-PDs. We hypothesize that ST leads to less belief strength of dysfunctional core beliefs. Furthermore, the short-term effects of both groups of techniques will be compared.

A secondary objective is to reduce the occurrence of dysfunctional schema modes (i.e., personality pathology in ST terms). We hypothesize that ST leads to a reduction in dysfunctional schema modes and an increase in functional modes.

A third objective is to reduce the occurrence of diagnostic criteria of PDs. We hypothesize that ST leads to a reduced occurrence of PD traits.

A fourth objective is a change in the severity of general mental health symptoms, related to mental disorders, like depression and anxiety disorders. We hypothesize that general mental health symptoms will be diminished by the given treatment.

Lastly, we hypothesize that ST will lead to an improvement in social interaction and communication. Our hypothesis is that more insight into one's own functioning through the given treatment will lead to an improvement in social interaction and communication.

7.3 Methods

7.3.1 Study design and procedure

This study is a concurrent multiple baseline design with a baseline varying in length from four to nine weeks. In this study, there are two treatment conditions (cognitive behavioral and experiential techniques) and two control conditions (baseline and exploration) in a within-subject design without a control group. This treatment design precludes the randomization to groups and blinding of treatment. We randomize the baseline length across participants to increase the internal validity of the case series design by varying the baseline duration from four to nine weeks over participants. We also randomize the order of starting with either cognitive behavioral or experiential interventions. The variation in baseline length and order makes it possible to differentiate between time effects and cognitive behavioral and experiential intervention effects. During the baseline phase, the 'treatment-as-usual'(TAU) is continued until six supportive sessions start in week 5 for participants 1 and 2; five supportive sessions start in week 6 for participants 3 and 4; four supportive sessions start for participants 5 and 6 in week 7; three supportive sessions start for participants 7 and 8 in week 8; two supportive sessions start for participants 9 and 10 in week 9; and one supportive session is given in week 10 for participants 11 and 12. In this way we can check whether meeting the therapist and attending sessions have an influence. Table 7.1 shows the 10-week period with four to nine weeks TAU-baseline and six to one week(s) with weekly supportive sessions. After baseline and supportive sessions, which for each participant covers a 10-week period in total, a five-week exploration phase follows with weekly sessions during which current and past functioning, psychological symptoms, and schema modes are explored, negative core beliefs are identified and explored, and information about the treatment is provided. The exploration phase is also used as a control for the effects of devoting attention to the participants' PD-related disabilities and problems. Then 15 weekly sessions with cognitive behavioral interventions are given followed by 15 weekly sessions with experiential interventions (or vice versa). Finally, there will be a 10-monthly follow-up with monthly schema therapy booster sessions.

Table 7.1 Baseline and supportive sessions phase – 10-week period with four to nine weeks TAU-baseline and six to one week(s) with weekly supportive sessions

	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Wk7	Wk8	Wk9	Wk10
Participant										
1	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP	SUP	SUP
2	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP	SUP	SUP
3	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP	SUP
4	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP	SUP
5	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP
6	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP	SUP
7	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP
8	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP	SUP
9	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP
10	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP	SUP
11	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP
12	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	TAU	SUP

SUP = Supportive session; TAU = Treatment-as-usual; Wk = week.

7.3.2 Ethical issues

The study procedure was reviewed and approved by the ethics committee of the University of Amsterdam (approved on 02 February 2016). A brochure with information about the study has been prepared for the participants. Written consent will be requested from the participants.

The anonymity of the participants will be guaranteed by removing identity information when analyzing the data. After a period of two years all data with names and identity information will be destroyed.

As a treatment integrity check, all therapists in this study are well trained and educated in CBT and ST, and are registered as a healthcare psychologist. To optimize treatment integrity, therapists received a four-day training in which the ST interventions were studied and practiced. During the study, the therapists will be two-weekly supervised by a clinical psychologist, who is a registered specialist in ST. All sessions will be audiotaped, and a random sample (at least one tape per participant per condition (baseline, exploration, CBT, experiential, follow-up) will be rated by a judge blind for condition on the type of techniques used to formally document treatment integrity.

7.3.3 Participants

The participants are 12 adult individuals from the mental health care institute Sarr Autism Rotterdam, the Netherlands. This institute is specialized in the psychodiagnostic assessment and psychotherapeutic treatment for children, adolescents, and adults with ASD.

Inclusion criteria are a primary diagnosis of DSM-IV and/or DSM-5 ASD and PD, age 18-65 years, with an IQ indicating at least normal intelligence (IQ > 80), at least a completed primary and secondary education, having a reasonable degree of insight into their own personality and recognition of their (psychological) functioning, and a willingness to participate in the study for two years confirmed by a signed informed consent.

Exclusion criteria are schizophrenia or other psychotic disorders, antisocial PDs, eating disorders, mental disorders secondary to medical conditions, mental retardation (IQ < 80), addiction (requiring clinical detox), and the presence of current suicidal ideation. Participants are not permitted to follow a concurrent psychological treatment at the same time. Pharmacotherapy can be used as a co-intervention during the treatment if already begun before the study intervention. This is no reason for exclusion from the study. In a longitudinal investigation of psychoactive and physical medication use among adolescents and adults with ASD, 88% of adults used at least one medication and 40% used three or more different types of medication (Esbensen et al. 2009). If participants need to start with pharmacotherapy or another form of (support) therapy during the study intervention, for example in case of an acute crisis, this will not lead to exclusion from the study, as long as this therapy and the results are documented precisely.

Participants can quit the study at any time for any reason if they wish to do so without any consequences. The researcher can decide to withdraw a participant from the study for urgent medical reasons.

7.3.4 Screening procedure

The screening procedure consists of two sessions in which participants are screened for eligibility to participate, based on the inclusion and exclusion criteria and in which the dysfunctional core beliefs are formulated. This screening is conducted by a registered clinical psychologist, qualified for and experienced in diagnostic assessments.

The diagnosis of ASD will be verified by studying the diagnostic report including the diagnosis of ASD based on a clinical evaluation of autism-specific behaviors by direct observation, plus a report of developmental and behavioral history and current functioning provided by partner, parent, or caregiver. The ASD must be diagnosed by a registered psychologist or psychiatrist. The *Social Responsiveness Scale – Adult version* (SRS-A; Constantino 2005; Noens et al. 2012) will be assessed for indications of severe shortcomings in social responsiveness, characteristic for adults with ASD.

Comorbid PD(s) will be assessed with the Dutch version of the *Structured Clinical Interview for Axis-II Personality Disorders* (SCID-II; (First et al. 1997; Weertman et al. 2000)). We further assess background information like sex, age, level of education, civil status, employment status, health, and medication use.

7.3.5 Interventions

The treatment protocol consists of 30 sessions, offered weekly, followed by 10 monthly booster sessions. A concurrent multiple baseline design will be used with the baseline varying from four to nine weeks, starting in week 5 and so on, with weekly supportive sessions varying from one to six week(s). After baseline and supportive sessions, a five-week exploration phase follows with weekly sessions during which current and past functioning, general mental health symptoms, schema modes are explored, and information about the treatment is given. This is followed by 15 weekly sessions with cognitive behavioral interventions and 15 weekly sessions with experiential interventions. Finally, there is a 10-month follow-up with monthly booster sessions. Participants are randomly assigned to baseline length. To counter any possible carryover effects, six of them are randomly assigned to first cognitive behavioral interventions followed by experiential interventions, whereas the other six participants start with experiential interventions followed by cognitive behavioral interventions. Table 7.2 shows an overview of the interventions.

7.3.6 Instruments and outcome measures

Primary outcome measure

Idiosyncratic belief strength: in direct discussion with each participant, three to five idiosyncratic beliefs are formulated that are central to the participant's problems. Participants will rate the degree to which they believe in each statement on 100 mm *visual analogue scales* (VAS; Freyd 1923) every week during treatment and monthly at follow-up. The average score constitutes the primary outcome. The VAS is a simple and frequently used scale measure and can be used for the assessment of variations in intensity of core beliefs. When responding to a VAS item, participants specify their level of agreement with a core belief by indicating a position along a continuous line between two end-points from 0 to 100. The core beliefs are formulated during the screening procedure by a registered clinical psychologist and participant. All participants rate the VAS core beliefs weekly during TAU baseline and supportive sessions phase, exploration phase, cognitive behavioral intervention phase, experiential intervention phase, and monthly during follow-up phase.

Table 7.2 Overview of the ST phases and interventions

Screening procedure – 2 sessions	
Session 1-2	Screening on the in- and exclusion criteria, administering SMI, SCL-90, SRS-A and SCID-II, formulating dysfunctional core beliefs, assessing background information.
Baseline and supportive sessions phase – 10-week period with four to nine weeks TAU-baseline and six to one week(s) with weekly supportive sessions by study therapist	
Week 5	Participants 1 and 2 start meeting therapist (6 supportive sessions).
Week 6	Participants 3 and 4 start meeting therapist (5 supportive sessions).
Week 7	Participants 5 and 6 start meeting therapist (4 supportive sessions).
Week 8	Participants 7 and 8 start meeting therapist (3 supportive sessions).
Week 9	Participants 9 and 10 start meeting therapist (2 supportive sessions).
Week 10	Participants 11 and 12 start meeting therapist (1 supportive session).
Exploration phase – 5 weekly sessions	
Session 1	Introduction to ST, and cognitive behavioural, and experiential interventions. Bonding. Psycho-education about core needs, functional, and dysfunctional behavior, links between present problems to childhood experiences.
Session 2	Psycho-education about core needs, functional, and dysfunctional behavior, links between present problems to childhood experiences, and cognitive-behavioural, and experiential interventions. Bonding.
Session 3-5	Conceptual mode model of the PD: Schema-focused case conceptualization and childhood antecedents of PD problems. Bonding.
Treatment phase – 15 weekly sessions of cognitive behavioral interventions	
Session 1-11	Correcting dysfunctional core beliefs, making early maladaptive schema modes less present in daily life by completing schema mode sheet, and a choice of psycho-education, past and actual test, pros and cons analysis, writing a positive diary, making a flash card, or a relapse prevention plan.
Session 12-14	Replacing dysfunctional core beliefs and behaviors with new, healthy cognitive, and behavioral options, making early maladaptive schema modes less present in daily life, behavioral pattern breaking by behavioral experiment/role-play.
Session 15	Evaluation.
Treatment phase – 15 weekly sessions of experiential interventions	
Session 1	Psycho-education experiential interventions, introducing imagery rescripting and two-chair work, and starting an imagery of a safe place.
Session 2-14	Choice of two-chair work or imagery rescripting of childhood memories, present, or future situations.
Session 15	Evaluation.
Follow-up phase – 10 monthly booster sessions	
Session 1-10	Maintaining and deepening changes.

PD = Personality Disorder; SCID-II = Structured Clinical Interview for DSM-IV Axis-II Personality Disorders; SCL-90 = Symptom Check List; SMI = Schema Mode Inventory; SRS-A = Social Responsiveness Scale – Adult Version; ST = Schema Therapy; TAU = Treatment-as-Usual.

Secondary outcome measures

The secondary outcomes include maladaptive schema modes assessed with the *Schema Mode Inventory* (SMI; Young et al. 2007), and PD criteria assessed with the SCID-II (First et al. 1997; Weertman et al. 2000). The SMI contains 118 items that correspond to 14 schema modes, each rated on a 1-6 point scale for frequency. The

Dutch version of the SMI will be used. All participants complete the SMI during screening procedure (i.e., before baseline), after baseline phase, after exploration phase, after cognitive behavioral intervention phase, after experiential phase, during and after follow-up phase. The SCID-II is a structured clinical interview assessing the ten DSM-IV PDs (American Psychiatric Association 2000). Each SCID-II PD trait has a scoring range of one to three. All participants are assessed by the SCID-II during screening, at 5-month follow-up, and at 10-month follow-up.

Another secondary outcome is severity of general mental health symptoms on *Symptom Check List* (SCL-90; Arrindell & Ettema 2003). The SCL-90 is a 90-item self-report questionnaire assessing general mental health symptoms during the last week. Each item consists of five statements, rated on a 1-4 point scale for severity, resulting in a total score of 90 to 450. The Dutch version of the SCL-90 will be used. All participants complete the SCL-90 during screening procedure, after supportive sessions phase, after exploration phase, after cognitive behavioral intervention phase, after experiential phase, at 5-month follow-up, and at 10-months follow-up.

The last secondary outcome is an improvement of social responsiveness on the SRS-A (Constantino 2005; Noens et al. 2012). The SRS-A is a 64-item self-report questionnaire measuring various dimensions of interpersonal behavior, communication, and rigid, repetitive behaviour, and interests, characteristic for adults with ASD. The items correspond to four treatment scales, i.e., Social Consciousness, Social Communication, Social Motivation, and Rigidity and Repetitiveness. Each item has four statements, rated on a 1-4 point scale. The Dutch version of the SRS-A will be used to assess improvement in social responsiveness by analyzing total scores and scores on the four treatment scales. All participants complete the SRS-A during screening procedure, after supportive sessions phase, after exploration phase, after cognitive behavioral intervention phase, after experiential phase, at 5-month follow-up, and at 10-month follow-up.

7.3.7 Study parameters

Primary study parameter

To test the first hypothesis, the following variable will be used: Belief Strength by VAS (dysfunctional core beliefs).

Secondary study parameters

To test the second hypothesis, i.e., to assess whether ST leads to dysfunctional schema modes occurring less frequently, and functional modes occurring more frequently, the manifestations of schema modes will be assessed with the SMI. To answer the third hypothesis, we will use the PD traits scores assessed with the SCID-

II. To answer the fourth hypothesis, we will use the total score of the SCL-90 (general mental health symptoms). To answer the fifth hypothesis, we will use the total and four subscale scores of the SRS-A (social interaction and communication).

7.3.8 Statistical analysis

We have chosen a concurrent multiple baseline design, because, just like a randomized controlled trial (RCT), it is able to demonstrate the occurrence of a change over time as being the result of an intervention (Hawkins et al. 2007; Onghena 2005). The concurrent multiple baseline design is practical, because it requires fewer participants. The loss of power is compensated by the fact that participants serve as their own controls and by the large number of assessments of the primary outcome. We are not aware of a systematic way to perform power analysis for the concurrent multiple baseline design. As an indication, the study would have 80% power to detect a change of Cohen's $d = 1$ or higher at $\alpha = .05$, two-tailed, if the paired t-test of the pre to post change were used to evaluate the treatment effect. A mixed regression analysis will be used for time, condition and time-within-treatment, which has been applied successfully in previous cases series studies. Mixed regression analysis will be used to assess the differences between the exploration, treatment (cognitive behavior and experiential) and follow-up conditions compared to the baseline. As an indication, we refer to the article of Arntz et al. (2013).

The effect of time will be tested by the linear time trend over the whole study period, with first baseline assessment as zero time point. Condition will be tested by five levels: baseline and supportive sessions phase, exploration phase, cognitive behavioral intervention phase, experiential intervention phase, and follow-up phase. Time-within-treatment will be tested by centered linear time effects within each of the conditions. For the analysis of core belief strength, we will follow a similar strategy as in Arntz et al. (2013) and Videler et al. (2018). First, a full model with time, condition (with baseline as reference), and time within each condition will be run, with for the repeated part an autoregressive (AR1) or autoregressive-moving-average (ARMA) structure, and if possible random intercepts and slopes for participant. If the linear time effect becomes non-significant (NS), it will be eliminated from the model. Next, NS time-within-condition effects will be eliminated step by step. We expect that both active treatment conditions will differ significantly from baseline, as follow-up will do. We expect time-within-condition to be significant, reflecting gradual reductions in belief strength during the two active conditions, with a NS difference between the two active conditions. The other variables (except the PD traits scores) will also be analyzed with mixed regression, now with a simpler model as no weekly assessments are available. The reduction in number of traits for the

initially diagnosed PD using the SCID-II between first (during screening procedure), second (at 5-month follow-up) and last (at 10-month follow-up) measurement will be tested using Wilcoxon's Signed Rank test.

7.4 Discussion

To the best of the authors' knowledge, so far no study has been published on the application of schema mode focused interventions in adults with ASD and comorbid PD(s). The aim of this study is to investigate the effectiveness of ST for PD psychopathology in adults with both ASD and PD. Our study investigates whether they can benefit from both cognitive behavioral and experiential interventions. We use cognitive behavioral interventions to target dysfunctional cognitions and beliefs, and to work on developing (social) skills. We use experiential interventions to alter the meaning of the childhood experiences and of present and future situations that have caused or contributed to the dysfunctional core beliefs and schema modes (see Arntz 2011).

The study is powered on the basis of paired t-test so that with 80% power a large pre-post effect size (Cohen's $d = 1$) can be detected at a significance level of .05. This effect size is based on previous studies into ST for PDs. In adults with ASD the effects might show to be weaker, but this can only be determined afterwards. On the other hand, the planned statistical analysis (mixed regression) and the many assessments of the primary outcome will lead to a higher power than a simple paired t-test of a twice assessed outcome.

A limitation of this study is that we did not consider using baseline length as a stratification factor when designing the study. As we already started the study, this cannot be revised. However, because we independently randomized TAU-baseline length and order, the combinations are random and we therefore don't expect substantial correlations between the two.

This study offers the first systematic test of administering ST to adults with ASD. The results of this study will provide initial evidence for the effectiveness of ST in treating adults with both ASD and PD(s). The study intends to provide valuable information for the future development and implementation of therapeutic interventions for adults with both ASD and PD(s).

8

Schema Therapy for personality disorders in adults with autism spectrum disorder: Results of a multiple case series study

Richard Vuijk, Mathijs Deen, Hilde M. Geurts, Arnoud Arntz

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Abstract

We investigated the effectiveness of Schema Therapy (ST) for adults with both autism spectrum disorder (ASD) and personality disorder (PD). A multiple case series design with 12 adults (aged 19–62 years; nine males, three females) was used, with baseline, exploration, ST (with cognitive behavioral and experiential techniques), and follow-up conditions. Participants rated dysfunctional core beliefs (primary outcome) weekly during baseline and treatment, and monthly during follow-up. Schema modes, general mental health symptoms, social responsiveness, PD-traits, and common Axis-I mental disorders were assessed. Mixed model analyses indicated significant effects of ST with medium to large effect sizes for dysfunctional core beliefs, functional schema modes, PD-traits, general mental health symptoms, and social responsiveness. Results remained stable during follow-up. ST seems effective in treating personality pathology in case of ASD-PD comorbidity.

Author contributions

All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Richard Vuijk and Mathijs Deen. The first draft of the manuscript was written by Richard Vuijk, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

8.1 Introduction

Autism spectrum disorder (ASD) is considered to be a neurodevelopmental condition with impairments in the social interaction and communication, as well as characteristic patterns of behavior and interests, need for a predictable and stable environment, and hypo- or hypersensitivity to sensory inputs. It is a lifelong challenge with symptoms starting from early childhood, even if these symptoms are not recognized until later (American Psychiatric Association 2013). High rates of mental health conditions are common in adults with ASD, ranging from 59%–69% suffering from mental disorders and symptoms (Buck et al. 2014; Kentrou et al. 2021) to 79% meeting criteria for a mental disorder at least once in their lives, with depression and anxiety as most common (Lever & Geurts 2016). The prevalence of meeting criteria for a personality disorder (PD) ranges from 48% to 62% among adults with ASD (Hofvander et al. 2009; Lugnegård et al. 2012). Results of a PD meta-analysis (Vuijk et al. 2018; see Chapter 3) show that obsessive-compulsive (32%), paranoid (24%), schizoid (24%), avoidant (23%), and schizotypal (14%) PDs are most common in adults with ASD.

The increased recognition of personality pathology in adults with ASD asks for interventions for personality pathology in this population. Until now, it is unknown whether there are effective and evidence-based psychosocial interventions for adults with ASD and comorbid PD. The *NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum* (NCCMH 2012) recommends interventions informed by existing NICE guidance for the specific comorbid condition with specific adaptations for ASD. The suggested adaptations are, for example, a more concrete and structured approach, a use of written and visual information, and making rules explicit and explaining the context (NCCMH 2012). When treating a comorbid condition, the therapist, therefore, must have an understanding of the challenges of adults with ASD and their possible impact on the treatment of comorbid mental disorders (NCCMH 2012). Moreover, individually tailored treatment is highly desirable according to a survey exploring the experiences of treatment and support of adults with ASD (Camm-Crosbie et al. 2019). The therapist needs to recognize that individuals with ASD often think differently as compared to the non-autistic population, therefore the therapist needs to be able to translate the concepts and components of the therapy in various ways (Gaus 2019). The central question in the current study is whether an established therapy for PD in adults, i.e., Schema Therapy (ST) can also be used as intervention for individuals with ASD.

ST, developed by Young (1990), for treating PDs is an integrative model of psychotherapy combining theory and techniques from Cognitive Behavioral Therapy, psychoanalytic object relations, attachment and other developmental theories, and Gestalt and other experiential therapies (Young et al. 2003). Particularly with the

more complex and severe PDs the schema mode model is one of the key elements of ST. Young et al. (2003) identified 10 schema modes each reflecting a constellation of emotions, cognitions, and behaviors, resulting from the activation of an early maladaptive schema and a specific way of coping with the schema activation. Whereas schemas are trait-like concepts, schema modes refer to states that people can be in. The goal of ST is to reduce dysfunctional schema modes and to increase functional schema modes, and to diminish the strength of the underlying early maladaptive schemas. Schema therapists make use of cognitive behavioral and experiential techniques. Clinicians often doubt whether experiential techniques are suitable for people with ASD, because of (assumed) difficulties and challenges in emotional information processing. Thus, it is important to investigate whether there is a positive response to experiential techniques in this population. There is more and more evidence that ST is an effective treatment for PDs in general (Bamelis et al. 2014; Giesen-Bloo et al. 2006) and also in special populations like older adults with PD (Videler et al. 2018). Will adults with ASD and comorbid PD be the next special population for which ST can be an effective treatment?

People with ASD have a vulnerability to maladaptive schema development, because of their challenges processing information about others, self, and nonsocial information resulting in social skill deficits and problems in self-management (Gaus 2019). A study of Oshima et al. (2015) revealed significantly higher scores for all the early maladaptive schemas apart from ‘self-sacrifice’ and ‘approval/recognition seeking’ in an adult ASD group compared to a non-ASD group. Early maladaptive schemas appear to account for mental health problems in adults with autism spectrum traits (Oshima et al. 2014). A single-arm preliminary study with an open trial design ($N = 10$, aged 20 to 39 years, five males, five females) indicated that individual ST is applicable as a treatment for young autistic adults with mental conditions (no PD) showing a significant reduction in early maladaptive schemas and improvement in quality of life and social adjustment (Oshima et al., 2018; Oshima et al., 2021).

The aim of the present study was to assess the effectiveness of individual ST as a treatment for PDs in adults with ASD, using a multiple case series design. Our hypotheses were that ST would lead to a decrease of dysfunctional core beliefs, dysfunctional schema modes, PD traits, general psychopathological symptoms, and DSM-IV Axis-I mental disorders, an increase of functional schema modes, and an improvement in social responsiveness.

8.2 Methods

8.2.1 Participants

Participants were 12 adult clients from Sarr Autism Rotterdam, a mental health institute specialized in ASD in the Netherlands. Inclusion criteria were: (1) primary diagnosis of ASD following the DSM-IV or DSM-5, and comorbid PD following DSM-IV. The PD was assessed with the Dutch version of the *Structured Clinical Interview for DSM-IV Personality Disorders* (SCID-II; Weertman et al. 2000); (2) age 18 to 65 years old; (3) at least a completed primary and secondary education; (4) having insight into their own personality and recognition of their psychological functioning (based on the impression of the clinical psychologist). Exclusion criteria were: (1) schizophrenia or other psychotic disorder; (2) antisocial PD; (3) eating disorder; (4) mental disorder secondary to medical condition; (5) intellectual disability ($IQ < 80$); (6) addiction requiring clinical detox; (7) current suicidal ideation. During the ST treatment no other form of psychotherapy was allowed except supportive therapy if needed. Pharmacotherapy was allowed. The 12 participants were recruited from 15 clients screened for participation; three declined to participate. Figure 8.1 presents the participant flow recruitment process.

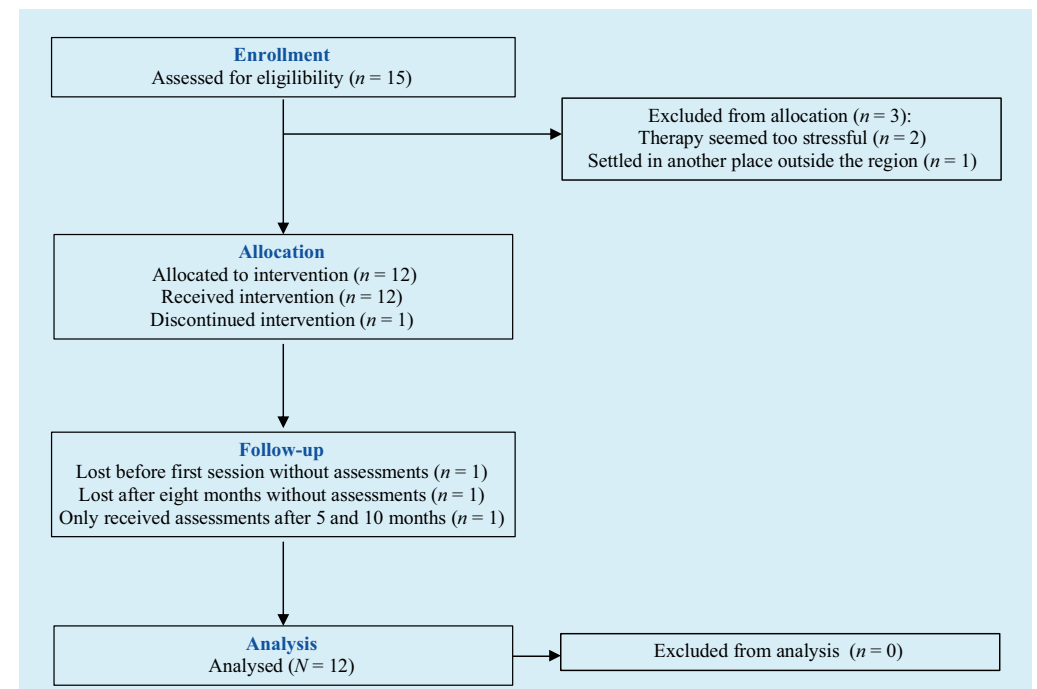


Figure 8.1 CONSORT flow diagram depicting the recruitment process

8.2.2 Design

We intended to use a multiple baseline case series design (see Vuijk & Arntz 2017; Chapter 7), because, just like a randomized controlled trial (RCT), it is able to demonstrate the occurrence of a change over time as being the result of an intervention (Hawkins et al. 2007; Onghena 2005). But because of a misunderstanding the four to nine weeks of baseline were immediately followed by one to six weeks of supportive sessions without an assessment between baseline and supportive sessions, finally resulting in a 10-week period of baseline and supportive sessions for all participants (Vuijk & Arntz 2017; Chapter 7). Because of the short duration of supportive sessions, time within supportive sessions condition could not be reliably estimated. For our primary outcome analysis we, therefore, combined baseline and supportive sessions in one condition, which for convenience reasons was labeled as baseline. So during the 10-week period of baseline and supportive sessions, 10 participants had no treatment and two participants continued 'treatment-as-usual' (TAU) until six supportive sessions started in week 5 for participants 1 and 2, five supportive sessions started in week 6 for participants 3 and 4, and so on till one supportive session started in week 10 for participants 11 and 12.

Thus, we used a multiple case series design. The design is practical, because it requires fewer participants than an RCT. The loss of power is compensated by the fact that participants serve as their own controls and by the large number of assessments of the primary outcome.

In this study, there were two ST conditions (cognitive behavioral and experiential techniques), a control condition (baseline), an exploration condition, and two follow-up conditions in a within-subject design. This design precludes blinding of treatment. We randomized the order of starting with either cognitive behavioral or experiential techniques in order to differentiate between time effects and treatment effects.

8.2.3 Measures

The primary outcome measure was based on a direct discussion with each participant at screening. Three dysfunctional beliefs were formulated by the participant with the help of a registered clinical psychologist. Participants rated the degree to which they believed in each statement on 100 mm *visual analogue scales* (VAS; Freyd 1923). The average sum score of the three dysfunctional beliefs constituted the final primary outcome.

The first secondary outcome measure was the *Schema Mode Inventory* (SMI; Young et al. 2007). The SMI contains 118 items that correspond to 14 schema modes, each rated on a 1-6 point scale for frequency. The SMI showed acceptable internal

consistencies of the 14 modes, adequate test-retest reliability and moderate construct validity (Lobbestael et al. 2010). We analyzed the dysfunctional and the Happy Child (functional) and Healthy Adult (functional) mode scores.

The second secondary outcome measure was the *Symptom Check List* (SCL-90; Arrindell & Ettema 2003). The SCL-90 is a 90-item self-report questionnaire assessing general mental health symptoms during the last week. Each item is rated on a 1-5 point scale for severity, resulting in a total score of 90 to 450. The SCL-90 showed good reliability and high internal consistency (Holi 2003). We analyzed the severity of psychopathological symptoms.

The third secondary outcome measure was the *Social Responsiveness Scale – Adult version* (SRS-A; Constantino 2005; Noens et al. 2012). The SRS-A is a 64-item self-report questionnaire measuring various dimensions of interpersonal behavior, communication and rigid, repetitive behavior and interests, characteristic for adults with ASD. Each item is rated on a 1-4 point scale. The SRS-A showed average to good internal consistency and test-retest reliability, adequate content validity, and good congruent validity (Noens et al. 2012). The SRS-A was used to assess improvement in social responsiveness by analyzing total scores.

The fourth secondary outcome was the PD criteria as assessed with the *Structured Clinical Interview for Axis-II Personality Disorders* (SCID-II; First et al. 1997). The SCID-II is a structured clinical interview assessing the ten DSM-IV PDs (American Psychiatric Association 2000). Each SCID II criterion has a scoring range of one to three. The SCID-II showed excellent inter-rater agreement (Lobbestael et al. 2011). We used the sumscore of the 1-3 ratings.

The fifth secondary outcome measure, added by a post-hoc decision during the trial, was the number of DSM-IV Axis-I mental disorders assessed with the *Standardized Assessment for Mental disorders* (SAM; Hoogduin 1999). This is a Dutch semi-structured interview to assess 16 DSM-IV Axis-I mental disorders most commonly seen in clinical practice. The SAM consists of 16 questions and subquestions. Psychometric properties of the SAM have not been studied yet. We analyzed the total scores of the 16 questions.

8.2.4 Assessments

All participants rated the VAS dysfunctional core beliefs weekly during baseline weeks, supportive sessions, exploration, cognitive behavioral and experiential techniques, and monthly during follow-up. Participants completed the Dutch SMI, SCL-90, and SRS-A at screening, after supportive sessions, exploration, cognitive behavioral techniques, experiential techniques, at 5-month, and 10-month follow-up. The Dutch SCID-II and the SAM were assessed at screening, 5-month, and 10-month follow-up.

8.2.5 Procedure

Adults with ASD and comorbid PD, who met inclusion criteria, were approached by the first author, until the number of 12 participants was reached. The screening procedure consisted of two sessions in which adults were screened for eligibility to participate, based on the inclusion and exclusion criteria, and in which the dysfunctional core beliefs were formulated. The diagnosis of ASD was verified by studying the diagnostic report. ASD had to be diagnosed by a registered psychologist or psychiatrist. Comorbid PD(s) and common DSM-IV Axis-I mental disorders were classified by using the SCID-II and SAM. We further assessed background information like sex, age, level of education, marital status, employment status, health, and medication use.

After the screening and baseline period, a 5-week exploration followed with weekly sessions during which current and past functioning, general mental health symptoms, early maladaptive schemas, dysfunctional core beliefs, and schema modes were explored, and information about the treatment was provided. The exploration was also used as a control for the effects of devoting attention to the participants' PD-related disabilities and problems. Then 15 weekly sessions with cognitive behavioral ST-techniques were given followed by 15 weekly sessions with experiential ST-techniques (or vice versa). Finally, there was a 10-month follow-up with monthly ST booster sessions.

8.2.6 Therapist training

The screening was conducted by a registered clinical psychologist (RV), qualified for and experienced in diagnostic assessments of ASD in adults. The follow-up assessments were administered by a health care psychologist qualified for and experienced in diagnostic assessments of ASD in adults.

All therapists in this study were trained in ST, were registered as a healthcare psychologist, and working with adults with ASD for at least five years. To optimize treatment integrity, therapists received a four-day ST training. During the study, the therapists were two-weekly supervised by a clinical psychologist, a certified ST supervisor. All sessions were audiotaped, and a random sample of at least three tapes per participant were rated with the *Schema Therapy Rating Scale for individual therapy sessions* (STRS-I-1; Young & Fosse 2005) by two judges to formally document treatment integrity. The STRS-I-1 was used to facilitate the blind assessment of the therapists whether they used the type of techniques associated with the phase concerned.

8.2.7 Statistical analysis

Data analyses were conducted using SPSS. A mixed model analysis was used with time, condition, and interaction as fixed predictors, which has been applied successfully in previous cases series studies (Arntz et al. 2013; Videler et al. 2018). We were not aware of a systematic way to perform power analysis for the design. As an indication, the study had 80% power to detect a change of Cohen's $d = 1$ or higher at $\alpha = .05$, two-tailed, if a paired t-test of the pre to post change would be used to evaluate the treatment effect. Effect sizes were calculated as change with respect to baseline, with baseline SD as denominator (with Cohen's $d = 0.2$ to be considered as a 'small' effect size, 0.5 a 'medium' effect size, and 0.8 a 'large' effect size). Change was based on the estimates from the mixed model analysis.

Primary outcome analysis

For the analysis of the dysfunctional core belief strengths a model with time, condition (with baseline as reference), and centered time within each condition was run, with an AutoRegressive (AR1) structure for the repeated part, and if possible random intercepts and random slopes for time at the participant level. If the linear time effect became non-significant, and fit of the model did not deteriorate as tested with a Chi-square test on the difference between -2LL values, it was eliminated from the model. Next, non-significant effects with $p \geq .10$ were eliminated step by step. We chose for either a random intercept, a random slope for time, or both, on the basis of the best fitting and most parsimonious model, using Chi-Square tests on the -2LL value and comparisons of AIC and BIC.

We first tested whether cognitive behavioral and experiential conditions differed in effectiveness, controlling for order. If not, the two conditions were combined into one ST condition to simplify the model. Next, we tested whether exploration, ST (or the separate components of ST), and follow-up conditions differed from baseline. We hypothesized that there would be a negative slope of time within ST, or within cognitive behavioral and experiential conditions if these conditions would differ, whereas no time effects within baseline condition were expected. We tested the time-within-follow-up effect, but did not have a clear hypothesis about it.

Secondary outcome analysis

For the analysis of SMI, SCL-90, and SRS-A we used the same approach as for the primary outcome. First, we tested whether there was a difference between the cognitive behavioral and experiential techniques. Second, we investigated whether a model with time, condition, or both was the best fitting. We tested our hypotheses by entering condition (with baseline as reference) in the fixed part. We chose for

either a random intercept, a random slope for time, or both, on the basis of the best fitting and most parsimonious model, using Chi-Square tests on the -2LL value and comparisons of AIC and BIC.

The reduction in number of symptoms for the initially diagnosed PD using the SCID-II between first (baseline), second (at 5-month follow-up), and last (at 10-month follow-up) measurement was tested using Wilcoxon's Signed Rank test. For the reduction in number of DSM-IV Axis-I mental disorders assessed with the SAM we used Friedman's test.

8.3 Results

8.3.1 Participants

Twelve (nine males, three females) native Dutch speaking individuals with ASD participated. Age ranged from 19 to 64 years (Mean age: 38 years). Three participants were partnered, nine were single. Level of education ranged from secondary school ($n = 2$) and higher vocational education ($n = 7$) to university ($n = 3$). Six participants were employed, three were unemployed, and three were student. All participants were diagnosed with at least one PD. Table 8.1 gives an overview of the demographic data of the participants. Table 8.2 gives an overview of the PD diagnoses and the mental disorder diagnoses of the participants.

Table 8.1 Demographic data of participants ($N = 12$)

Participant	Age	Gender	Marital status	Education	Employment	ASD diagnosis	Medication
1	62	M	Married	Secondary school	Employed	Asperger's disorder	Antidepressant
2	42	F	Single	Higher vocational education	Unemployed	PDD-NOS	
3	61	M	Single	Higher vocational education	Employed	Asperger's disorder	
4	42	M	Divorced	Higher vocational education	Unemployed	Asperger's disorder	Antidepressant Antipsychotic Anxiolytic
5	23	M	Single	Higher vocational education	Student	Asperger's disorder	
6	30	M	Single	University	Employed	Asperger's disorder	Antidepressant
7	36	F	Married	Secondary school	Employed	PDD-NOS	
8	44	M	Single	University	Employed	Asperger's disorder	
9	27	M	Single	Higher vocational education	Student	ASD	
10	52	M	Single	University	Unemployed	Asperger's disorder	
11	19	M	Single	Higher vocational education	Student	PDD-NOS	Antidepressant
12	29	F	Partnered	Higher vocational education	Employed	PDD-NOS	Antidepressant

ASD = Autism spectrum disorder; F = Female; M = Male; PDD-NOS = Pervasive developmental disorder - not otherwise specified

Table 8.2 DSM-IV Personality disorder and DSM-IV axis-I mental disorder diagnoses (*N* = 12) assessed at screening (baseline), 5- and 10-month follow-up

Participant	Screening	After 5-month follow-up	After 10-month follow-up
1	Avoidant, Obsessive-Compulsive, Depressive PDs; PD-NOS Dependent Major Depressive Disorder	?	?
2	Obsessive-Compulsive PD Panic Disorder with agoraphobia Social Anxiety Disorder Generalized Anxiety Disorder	Obsessive-Compulsive PD Panic Disorder with agoraphobia Social Anxiety Disorder Generalized Anxiety Disorder Persistent Depressive Disorder	PDNOS Obsessive-Compulsive Panic Disorder with agoraphobia Generalized Anxiety Disorder Somatic Symptom Disorder
3	Obsessive-Compulsive PD Adjustment Disorder with depressed mood	PDNOS Obsessive-Compulsive, Passive-Agressive o	PDNOS Obsessive-Compulsive Adjustment Disorder with depressed mood
4	Avoidant, Depressive, Borderline PDs Social Anxiety Disorder Major Depressive Disorder	- Social Anxiety Disorder Somatic Symptom Disorder	PDNOS Avoidant Social Anxiety Disorder Somatic Symptom Disorder
5	Avoidant, Depressive PDs; PDNOS Dependent, Obsessive-Compulsive, Paranoid Attention-Deficit Disorder Obsessive-Compulsive Disorder Generalized Anxiety Disorder	Obsessive-Compulsive PD; PDNOS Avoidant, Depressive Attention-Deficit Disorder Obsessive-Compulsive Disorder	PDNOS Obsessive-Compulsive Attention-Deficit Disorder Obsessive-Compulsive Disorder Generalized Anxiety Disorder
6	Avoidant, Obsessive-Compulsive, Depressive, Schizoid PDs; PDNOS Dependent, Paranoid Major Depressive Disorder Social Anxiety Disorder Panic Disorder with agoraphobia	- o	- o

Table 8.2 Continued

Participant	Screening	After 5-month follow-up	After 10-month follow-up
7	Avoidant PD o	PDNOS Avoidant Anorexia Nervosa	Avoidant PD Anorexia Nervosa
8	Avoidant, Dependent, Obsessive-Compulsive, Depressive PDs Major Depressive Disorder Social Anxiety Disorder Somatic Symptom Disorder	Obsessive-Compulsive, Depressive PDs Major Depressive Disorder Social Anxiety Disorder	Obsessive-Compulsive, Depressive PDs Major Depressive Disorder Social Anxiety Disorder
9	Obsessive-Compulsive, Depressive, Narcissistic PDs; PDNOS Paranoid Major Depressive Disorder Generalized Anxiety Disorder	Obsessive-Compulsive PD Major Depressive Disorder Substance Dependence	Obsessive-Compulsive PD Substance Dependence
10	Avoidant, Obsessive-Compulsive PDs; PDNOS Passive-Agressive, Depressive Persistent Depressive Disorder Post-Traumatic Stress Disorder	Obsessive-Compulsive, Paranoid PDs Persistent Depressive Disorder Post-Traumatic Stress Disorder	Obsessive-Compulsive PD; PDNOS Depressive, Paranoid Persistent Depressive Disorder Post-Traumatic Stress Disorder
11	Obsessive-Compulsive, Depressive PDs; PDNOS Avoidant Panic Disorder without agoraphobia Social Anxiety Disorder	Obsessive-Compulsive, Borderline PDs; PDNOS Depressive Major Depressive Disorder Generalized Anxiety Disorder	Avoidant PD; PDNOS Borderline o
12	Avoidant, Obsessive-Compulsive, Depressive PDs Major Depressive Disorder Persistent Depressive Disorder Social Anxiety Disorder Obsessive-Compulsive Disorder Generalized Anxiety Disorder	? ?	? ?

PD Personality disorder; PDNOS Personality disorder not otherwise specified;
 ? = Assessment was not possible; - = No PD diagnosis; o = No mental disorder diagnosis.
 PD diagnoses assessed with SCID-II. DSM-IV axis-I mental disorders assessed with SAM.

8.3.2 Attrition

Participant 1 declined participation at follow-up because of a sick partner. Participant 5 chose to quit therapy, because he wanted to start pharmacotherapy which was not indicated by the psychiatrist. Nevertheless he filled out all measures, and participated in the follow-up assessments. Participant 12 declined participation at follow-up because of finding a new job resulting in severe psychological distress. Table 8.3 shows an overview of the assessments and sessions per condition for all participants.

8.3.3 Treatment integrity

To judge treatment integrity 43 audio tapes (seven supportive sessions, 12 exploration sessions, 12 cognitive behavioral sessions, 12 experiential sessions) were rated by judging the phase and the techniques associated with the phase concerned. Judge one (RV) rated 43 audio tapes, and the other judge, a student psychologist, rated nine of the 43 audio tapes. With both judges a score of 91% (RV) and 89% (the other judge), and a strong interrater agreement of .83 (Cohen's kappa; $p < .001$) were found for using the correct techniques per condition by the therapists.

8.3.4 Primary outcome

The individual averaged VAS-scores specifying the credibility of dysfunctional core beliefs during the five conditions are shown in Figure 8.2. Visual inspection shows large decreases for participants 2, 4, 6, 7, and 9. Participants 1, 3, 10, and 12 have more or less unchanged scores. Participants 8 and 11 have an irregular score pattern.

First, we tested the difference between the two ST type conditions. The differences between time effects and main effects of cognitive behavioral and experiential techniques failed to reach significance, controlled for their order of application. The two conditions were therefore combined into one ST condition. For the analysis of all scores a random intercept had the best fit. A model with only time as fixed predictor revealed a significant effect of time, with belief scores reducing with time, $p < .01$. However, when the conditions and time-within-condition were added, the general time effect became non-significant, and model fit did not significantly deteriorate when time was deleted from the model. Table 8.4 presents the final results of the mixed model analyses after stepwise deletion of time within condition effects with a significance level $\geq .10$. In sum, the results showed that the main effects of ST and follow-up conditions were significant compared to baseline with medium to large effect sizes. Time-within-condition was significant for ST and follow-up with medium to large effect sizes, showing a continuing decrease over time of belief strength after the start of ST, whereas the time effects within baseline and exploration were non-significant and were deleted from the model.

Table 8.3 Overview of the assessments and sessions per condition for the participants ($N = 12$)

Participants	A1	Baseline Weeks	Supportive Sessions	A2	Exploration Sessions	A3	ST Sessions 1-15	A4	ST 2 Sessions 16-30	A5	Follow-up Months 1-5	A6	Follow-up Months 6-10	A7
1	x	6	4	x	5	X	15 Exp	x	15 CB	x	5	x	-	-
2	x	5	5	x	5	X	15 Exp	x	15 CB	x	5	x	5	x
3	x	9	1	x	5	X	15 CB	x	15 Exp	x	5	x	5	x
4	x	7	3	x	5	X	15 CB	x	15 Exp	x	5	x	5	x
5	x	8	2	x	5	X	15 Exp	x	9 CB	x	-	x	-	x
6	x	4	6	x	5	X	15 Exp	x	15 CB	x	5	x	5	x
7	x	5	5	x	5	X	15 CB	x	15 Exp	x	5	x	5	x
8	x	9	1	x	5	X	15 CB	x	15 Exp	x	5	x	5	x
9	x	6	4	x	5	X	15 Exp	x	15 CB	x	5	x	5	x
10	x	8	2	x	5	X	15 Exp	x	15 CB	x	5	x	5	x
11	x	7	3	x	5	X	15 CB	x	15 Exp	x	5	x	5	x
12	x	4	6	x	5	X	15 CB	x	15 Exp	x	5	x	5	-

A1-A7 = Assessment; CB = Cognitive behavioral techniques; Exp = Experiential techniques; ST = Schema therapy; x = Participant completed assessment; - = Participant declined assessment. Participant 1 declined after five months follow-up. Participant 5 declined after nine sessions of CBT, but still participated in the assessments. Participant 12 declined after eight months follow-up.

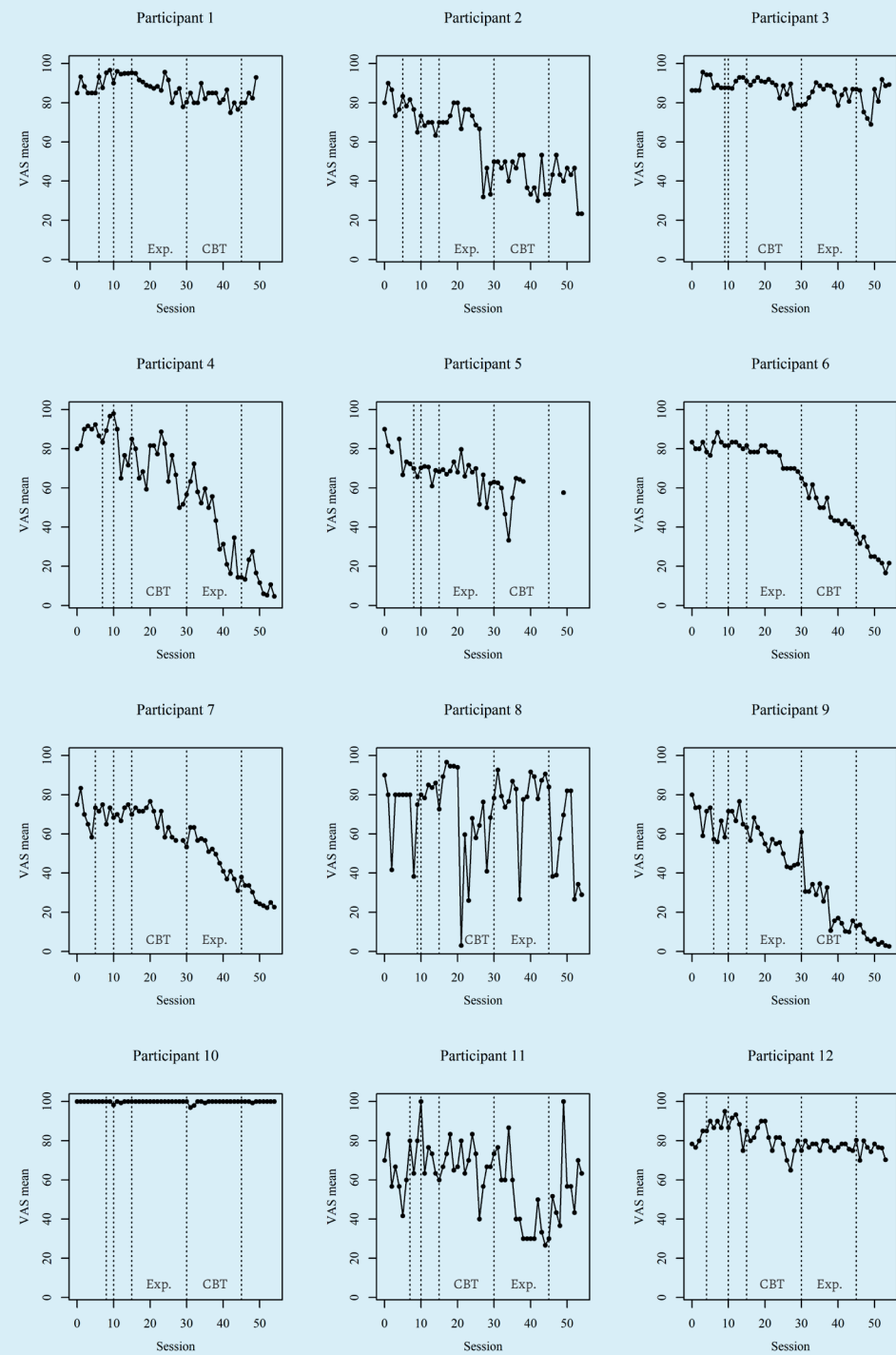


Figure 8.2 Individual average credibility ratings of dysfunctional core beliefs ($N = 12$)
Exp = Experiential techniques; CBT = Cognitive behavioral techniques; VAS = Visual Analogue Scale.

Table 8.4 Results of mixed model analyses

	Estimate	SE	df	t	p	CI	Effect size ^a (Cohen's <i>d</i>)
VAS Dysfunctional core beliefs							
Intercept (baseline)	80.78	2.70	14.42	29.97	≤0.001	(75.02 - 86.55)	
Exploration	1.16	2.26	240.28	.51	0.608	(-3.29 - -5.61)	
ST	-10.92	3.86	20.55	-2.83	0.010	(-18.96 - -2.89)	0.852
Session in ST	-0.87	.17	27.09	-5.05	≤0.001	(-1.22 - -0.52)	2.038
Follow-up	-26.62	6.71	17.17	-3.97	0.001	(-40.76 - -12.49)	2.078
Session in follow-up	-.80	.47	246.57	-1.69	0.092	(-1.72 - 0.13)	0.624
SMI Happy Child							
Intercept (baseline)	2.48	.14	23.10	17.17	≤0.001	(2.18 - 2.77)	
After Supportive sessions	.22	.11	53.08	2.08	0.042	(0.01 - 0.44)	0.383
After Exploration	.33	.13	57.80	2.60	0.012	(0.07 - 0.58)	0.574
After 15 ST sessions	.26	.14	41.37	1.90	0.066	(-0.02 - 0.53)	
After 30 ST sessions	.61	.14	30.18	4.28	≤0.001	(0.32 - 0.90)	1.061
After 5-month Follow-up	.38	.15	25.33	2.58	0.016	(0.08 - 0.68)	0.661
After 10-month Follow-up	.55	.15	22.86	3.97	0.001	(0.25 - 0.88)	0.956
SMI Healthy Adult							
Intercept (baseline)	3.63	.17	30.22	22.06	≤0.001	(3.29 - 3.96)	
After Supportive sessions	-0.03	.15	50.12	-0.18	0.860	(-0.33 - 0.27)	
After Exploration	.08	.17	59.00	.49	0.627	(-0.26 - 0.42)	
After 15 ST sessions	-0.06	.18	44.56	-0.32	0.749	(-0.42 - 0.31)	
After 30 ST sessions	.22	.19	35.23	1.17	0.250	(-0.16 - 0.59)	
After 5-month Follow-up	.21	.19	32.01	1.11	0.275	(-0.18 - 0.60)	
After 10-month Follow-up	.49	.20	30.66	2.47	0.019	(0.09 - 0.89)	0.702
SMI Dysfunctional Modes							
Intercept (baseline)	2.77	.13	17.82	20.78	≤0.001	(2.49 - 3.05)	
After Supportive sessions	.09	.09	51.13	0.97	0.335	(-0.10 - 0.28)	
After Exploration	.13	.10	57.84	1.31	0.195	(-0.07 - 0.33)	
After 15 ST sessions	.03	.10	47.22	0.29	0.770	(-0.18 - 0.24)	
After 30 ST sessions	-0.13	.10	42.18	1.24	0.223	(-0.34 - 0.08)	
After 5-month Follow-up	-0.13	.11	41.42	1.27	0.212	(-0.35 - 0.08)	
After 10-month Follow-up	-0.21	.11	41.03	1.93	0.061	(-0.43 - 0.01)	
SCL-90							
Intercept (baseline)	228.67	13.95	25.57	16.39	≤0.001	(199.97 - 257.37)	
After Supportive sessions	-9.71	11.89	48.95	-0.82	0.418	(-33.61 - 14.19)	
After Exploration	-11.80	13.38	56.35	-0.88	0.381	(-38.60 - 15.00)	
After 15 ST sessions	-21.00	13.74	39.39	-1.53	0.134	(-48.78 - 6.78)	
After 30 ST sessions	-35.17	13.97	31.43	-2.52	0.017	(-63.63 - -6.70)	0.694
After 5-month Follow-up	-28.42	14.35	29.29	-1.98	0.057	(-57.77 - 0.93)	
After 10-month Follow-up	-53.15	14.80	28.46	-3.59	0.001	(-83.45 - -22.85)	1.049
SRS-A							
Intercept (baseline)	93.75	6.76	18.31	13.86	≤0.001	(79.56 - 107.94)	
After Supportive sessions	-3.85	5.47	41.49	-0.71	0.485	(-14.89 - 7.18)	
After Exploration	-4.03	5.05	54.89	-0.80	0.429	(-14.15 - 6.10)	
After 15 ST sessions	-5.92	4.95	59.59	-1.20	0.237	(-15.82 - 3.98)	
After 30 ST sessions	-15.75	4.95	59.17	-3.19	0.002	(-25.65 - -5.85)	0.724

Table 8.4 Continued

	Estimate	SE	df	t	p	CI	Effect size ^a (Cohen's <i>d</i>)
After 5-month Follow-up	-14.43	5.08	59.20	-2.84	0.006	(-24.59 - -4.27)	0.663
After 10-month Follow-up	-18.28	5.22	59.02	-3.50	0.001	(-28.73 - -7.82)	0.840

CI = Confidence interval at 95%; SCL-90 = Symptom Check List 90; SMI = Schema Mode Inventory; SRS-A = Social Responsiveness Scale – Adult version; ST = Schema therapy; VAS = Visual analogue scale.

^aEffect size calculated as change with respect to baseline, with baseline SD as denominator. Change based on the estimates from the mixed model analysis.

8.3.5 Secondary outcomes

For all secondary measures that were analyzed with mixed regression, the cognitive behavioral and the experiential techniques did not differ significantly (see Table 8.5), and therefore the conditions were combined into one ST condition. Moreover, for all a random intercept for participant yielded the best fit. Lastly, for all except dysfunctional schema modes, a model with condition had a superior fit above a model with time or with both time and condition. For dysfunctional schema modes, a model with only time had a superior fit, thus any conclusions from tests of condition remain unclear as time (and associated nonspecific factors) might be a better explanation than condition effects. Table 8.4 and Figure 8.3 present the final results of the mixed model analyses for the SMI, SCL-90, and SRS-A after adding random intercepts and with a significance level of $< .05$.

Table 8.5 Estimated means on SMI, SCL-90 and SRS-A for the contrast cognitive behavioral or experiential techniques first

	Contrast cognitive-behavioral versus experiential techniques				
	Estimated means	SE	df	t	p
SMI Happy Child	0.15	0.08	10.1	1.82	0.10
SMI Healthy Adult	0.06	0.16	10	0.37	0.72
SMI Dysfunctional Modes	0.159	0.11	9.97	1.45	0.18
SCL-90	16.2	10.4	9.97	1.56	0.15
SRS-A	6.67	4.97	9.89	1.34	0.21

SCL-90 = Symptom Check List 90; SMI = Schema Mode Inventory; SRS-A = Social Responsiveness Scale – Adult version

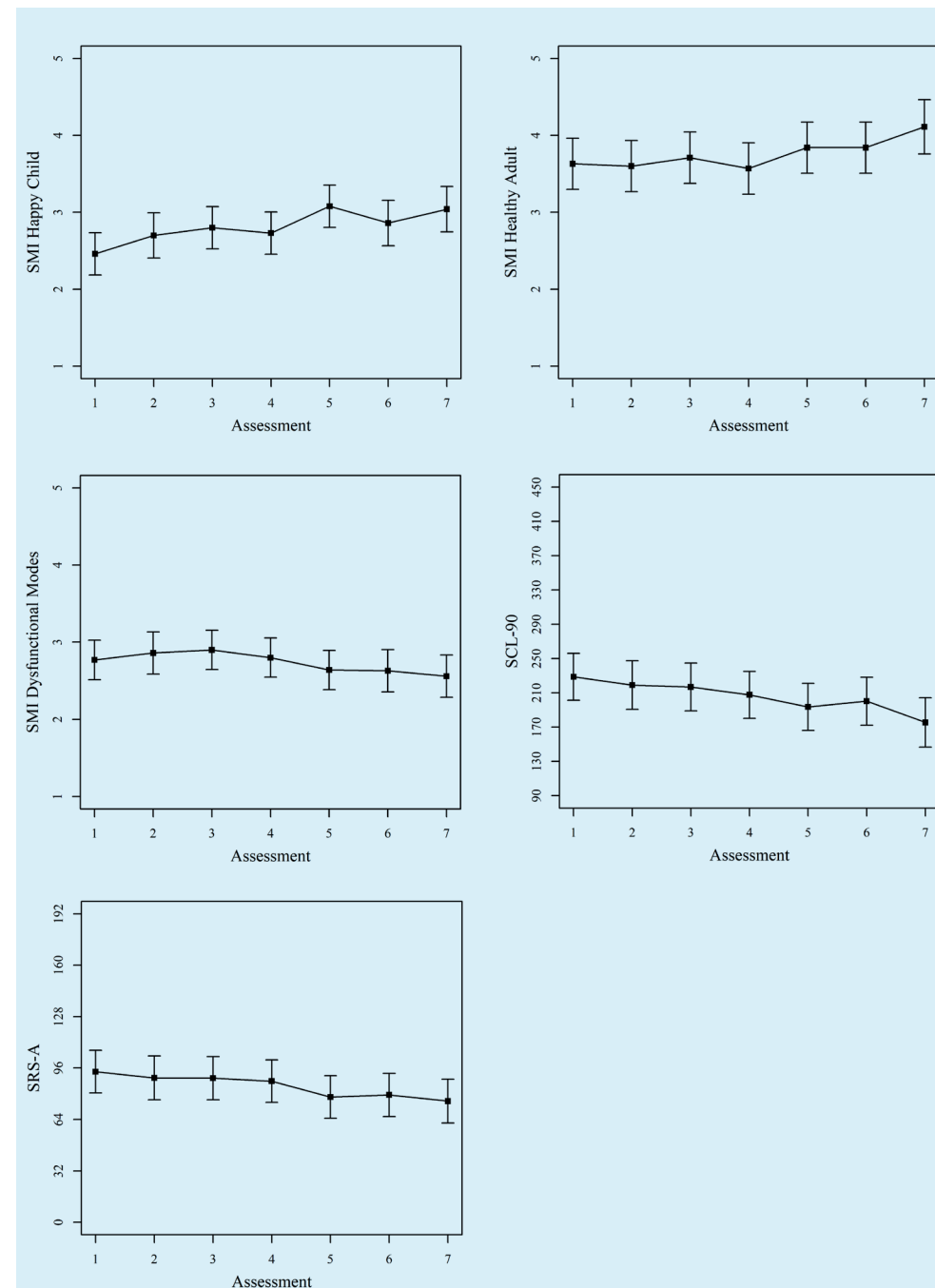


Figure 8.3 Estimated marginal means of total scores of SMI, SCL-90 and SRS-A ($N = 12$)

Assessments: 1 = baseline; 2 = after supportive sessions; 3 = after exploration; 4 = after 15 sessions schema therapy; 5 = after 30 sessions schema therapy ; 6 = after 5-month follow-up; 7 = after 10-month follow-up. SCL-90 = Symptom Check List 90; SMI = Schema Mode Inventory; SRS-A = Social Responsiveness Scale – Adult version.

Change in schema modes (SMI)

For Happy Child mode, changes appeared significant with medium to large effect sizes for all conditions except for the first 15 sessions of ST compared to baseline. For Healthy Adult and dysfunctional modes changes were non-significant, except for Healthy Adult mode after 10-month follow-up compared to baseline, with a medium effect size.

Change in general mental health symptoms (SCL-90)

Changes in general mental health symptoms assessed with the SCL-90 appeared significant after the second period of ST and after 10-month follow-up compared to baseline, with a medium to large effect size.

Change in social interaction and communication (SRS-A)

Changes in social interaction and communication assessed with the SRS-A were significant after the second period of ST and at both follow-up conditions compared to baseline. Effect sizes of treatment versus baseline were medium, and follow-up versus baseline were medium to large.

Change in personality disorder traits (SCID-II)

Table 8.2 shows an overview of the PDs measured at screening (= baseline) and follow-up. Four participants with PD diagnoses at baseline did not meet full criteria for a specific PD diagnosis anymore at follow-up, now diagnosed as PD not otherwise specified (PDNOS). One participant did not meet any criteria for a specific PD nor PDNOS anymore at follow-up. In one participant PD diagnosis did not change from baseline to follow-up. One participant assessed with four PD diagnoses including one PDNOS only had one specific PD at follow-up. One participant with four specific PD diagnoses only met full criteria for two specific PDs at follow-up. Two participants assessed with three PDs including one PDNOS only met full criteria for one specific PD and PDNOS at follow-up. Two participants were not reassessed for PD diagnosis because of declining follow-up participation.

The number of SCID-II PD-traits decreased significantly with large effect sizes between baseline (Median = 26; IQR = 7.5) and 5-month follow-up (Median = 13; IQR = 9; $r = -.68$), $p = .01$, as well as between baseline and 10-month follow-up (Median = 9.5; IQR = 5.5; $r = -.63$), $p = .005$.

Change in DSM-IV Axis-I mental disorders (SAM)

Table 8.2 shows an overview of the general DSM-IV Axis-I mental disorders measured at screening (= baseline) and follow-up. For 10 of the 12 participants (two declined participation at follow-up assessment) the number of DSM-IV Axis-I mental disorders decreased between baseline (Mean = 2.0, SD = .94) and 5-month

follow-up (Mean = 1.8, SD = 1.23), as well as between baseline and 10-month follow-up (Mean = 1.8, SD = 1.23). There was no significant difference between the repeated measurements, according to the Friedman's test ($\chi^2(2) = .07$, $p = .97$).

8.4 Discussion

This study explored the effects of ST for adults with ASD and comorbid PD using a non-concurrent multiple case series design. Our findings confirmed our hypothesis that ST would significantly lead to a decrease of dysfunctional core beliefs, PD-traits, general mental health symptoms, an increase of the functional Happy Child mode, and an improvement of social responsiveness. The changes consolidated after treatment, indicated by 5- and 10-month follow-ups. For the functional Healthy Adult mode we only found a significant increase at 10 month follow-up. Our findings could not confirm that ST would lead to a decrease of dysfunctional schema modes and DSM-IV Axis-I mental disorders. Our findings demonstrated no evidence for order in starting with cognitive behavioral or experiential techniques, and no superiority for one of these two techniques.

Remarkably, the dysfunctional schema modes did not decrease in our study. Given the focus of ST on schema modes, this finding is hard to interpret. One explanation might be that these modes are persistent due to the vulnerability to maladaptive schema development in people with ASD (Gaus 2019), though the changes in core beliefs contradict this explanation. Another explanation might be that the modification of ST for people with ASD perhaps leads to a form of ST that primarily strengthened functional modes, while not successfully addressing the dysfunctional modes. Perhaps the rigidity in some adults with ASD might have hindered change in the frequency of dysfunctional schema mode activation, and further adaptations of ST are required to break this rigidity. Visual inspection of the individual average credibility of dysfunctional core beliefs (Fig. 8.2) of the participants shows a dichotomy: some recognize change in their dysfunctional core beliefs and modes, while others (participants 1, 3, 10, and 12) seem to adhere to them. These four participants still benefit from treatment, albeit less than the other participants, because they do show an improvement on the functional modes, which is also reflected in an improvement on the secondary outcome measures. A previous study indicated that the functional Healthy Adult mode as well as the dysfunctional Vulnerable Child mode are central to the change process in the treatment of PD (Yakin et al. 2020). The rigid participants seemed to benefit only from one improvement mechanism (i.e., increasing functional modes) and not from the second mechanism (i.e., a decrease in dysfunctional modes).

We do not have an explanation for an unexpected significant increase of functional Happy Child mode after supportive sessions and exploration other than that starting a treatment participants were looking forward to and meeting the therapist contributed to feelings of optimism, understanding, protection, and validation. Participant 2 stated at follow-up, that this was her first intensive and long lasting treatment in which she felt really welcome and understood by the therapist, who she described as relaxed, patient, open, clear, with a sense of humor, and ASD experienced. The explanation for the functional Healthy Adult mode only to be increased after 10-month follow-up is that it is a complex and long way dealing with ASD and PD related challenges. It takes time to develop positive and functional thoughts and feelings about oneself, and enough ability to deal with dysfunctional schema modes. A possible explanation for an improvement of social interaction and communication is given by participant 4: ST gave him the opportunity to practice his social skills over a longer period of time with lots of explanation, discussion, and recurrence of practicing. Our study did not find superiority for cognitive behavioral techniques over experiential techniques. Both techniques did quite well. Contrary to what some may expect, people with ASD can also benefit from experiential techniques. Participant 11 found imagery rescripting very useful, especially the explaining, translating, and discussing afterwards leading to meaningful insight in his feelings.

Treatment of mental health conditions research in people with ASD is scarce. In line with a survey exploring experiences of treatment and support of adults with ASD (Camm-Crosbie et al. 2018), there is an urgent need for validated treatment approaches and therapists trained in people with ASD and co-occurring mental health difficulties and disorders. To improve treatment for adults with ASD and comorbid PD, we advise more specific studies of therapies like ST for them. Our findings emphasize the essence that researchers continue to refine the interventions for personality pathology in people with ASD for optimal effectiveness of the interventions. Future studies should address the issue to what degree ST techniques can be used in adults with ASD and comorbid PD to reduce the dysfunctional schema modes. Future studies will be needed to further analyze the degree of benefit of ST in people with ASD and comorbid PD. Replication of our findings in a RCT is needed.

Strengths of this study are the use of three independent study therapists supervised by an independent clinical psychologist/schema therapist during the whole study, the assessments at screening and follow-up by two independent raters, treatment integrity check, randomization of the order of starting with either cognitive behavioral or experiential techniques over participants, the fact that medication was constant, and no other treatment was followed by the participants.

There are several limitations of this study. First, as already mentioned, the change of our multiple baseline case series design into a multiple case series design especially influenced the possibility to draw causal conclusions from our primary outcome analysis because the evidence that occurrence of change as a result of the intervention instead of time is less strong. Second, 10 participants were already in treatment at the institute, unknown if they had already taken more or less some advantage of that treatment when starting to participate in this study. Third, participants differed greatly in the number of DSM PD diagnoses and secondary DSM-IV Axis-I mental disorder diagnoses, unknown if this variety influenced the results: one can imagine that participants with more diagnoses have had less improvement.

Overall, as far as we know, our study is the first systematic investigation offering preliminary support for the effectiveness of PD treatment in adults with ASD. The results of this study indicate that ST might be effective in decreasing dysfunctional core beliefs, PD traits, general mental health symptoms and increasing functional schema modes and social responsiveness. Improvements well maintained over time were seen.

General Discussion



9

Adults with autism spectrum disorder: Diagnostic assessment, personality (pathology), and psychotherapy - General discussion

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9.1 Introduction

In this thesis, diagnostic assessment, personality (pathology), and psychotherapy in adults with autism spectrum disorder (ASD) were studied. This thesis consists of three parts: (I) diagnostic assessment (Chapter 2), (II) personality (pathology) (Chapters 3, 4, and 5), and (III) psychotherapy (Chapters 6, 7, and 8).

In this final chapter, the general discussion, I present the summary of the main findings, and I discuss the methodological considerations (including study designs, statistical analysis, strengths, and limitations) and clinical relevance emerging from these studies. Recommendations for future research and key findings are given.

9.2 Main findings

9.2.1 Diagnostic assessment of ASD in adults

In Chapter 2, we explored the utility of a new ASD assessment instrument for adults, the *Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults* (NIDA) (Vuijk 2016; see Appendices 1 and 2), by determining the psychometric properties of the instrument. We examined the interrater agreement, the convergent validity including the sensitivity and specificity, and the concurrent criterion-related validity of the in-person current functioning part of the interview. A total number of 90 adult males (30 males with ASD, 30 males with personality disorder (PD), and 30 nonpatient males), aged 18-65 years, without intellectual disability participated. The NIDA and the *Autism Diagnostic Observation Schedule – Second edition* (ADOS-2; Lord et al. 2012; Dutch version: De Bildt et al. 2013) were administered to all participants. The results indicated a preliminary sound psychometric evaluation of an important part of the NIDA when used in males as: a) the interrater agreement; b) the convergent validity with the ADOS-2 and the clinical diagnosis of ASD; c) the sensitivity and the specificity; and d) the concurrent criterion-related validity were all very good. The NIDA and ADOS-2 showed a comparable discrimination between males with ASD, males with PD, and males without either ASD or PD. When administering the NIDA and the ADOS-2 simultaneously we have found similar sensitivity and specificity scores as when using either one of both. These findings show promising for future psychometric NIDA studies in a more diverse population (e.g., also including adults with social anxiety disorder and avoidant PD).

9.2.2 Personality (pathology) in adults with ASD

In Chapter 3, we systematically reviewed studies of personality and the dimensions of temperament and character, personality pathology, and PDs in adult males and females with ASD. We conducted searches of articles in Ovid MEDLINE

1996 to present, and Embase 1996 to present, following the *Preferred Reporting Items for Systematic Reviews and Meta-Analysis* (PRISMA; Moher et al. 2009). We included 15 studies for the review, from which seven studies were meta-analyzed. Results indicated a significant and systematic association between ASD and a temperament characterized by introversion, rigidity, passive-dependence with low novelty seeking, high harm avoidance, low reward dependence, and high persistence. We found adults with ASD having a risk for deficits in character development with low Self-Directedness, low Cooperativeness, and high Self-Transcendence. We found ASD traits and Neuroticism to be positively correlated, as well as ASD traits and Extraversion, Openness to Experience, Agreeableness, and Conscientiousness to be negatively associated. Furthermore, ASD was positively correlated with paranoid, schizoid, schizotypal, avoidant, and obsessive-compulsive PDs. The different associations indicated a considerable variation in personality and personality pathology between people with ASD. For a complete picture of an individual with ASD and for implementation of the most effective treatment interventions for and therapeutic bonding with adults with ASD, we advised to consider temperament, character, and comorbid personality pathology and PDs.

In Chapter 4, we focused on temperament and character dimensions in adult males with ASD. In our 2012 study we published in a Dutch journal (Vuijk et al. 2012) and in three earlier studies, the ASD male participants were generally group matched (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002). In our current study, we investigated if same results on temperament and character dimensions would be obtained by individual case matching as closely as possible on age, education, and marital status. In this study, we reanalyzed scores on the *Temperament and Character Inventory* (TCI; Cloninger et al. 1993) of a group of 66 normally intelligent males, aged 18-63 years, diagnosed with ASD, by individual case matching to a comparison group of 66 males from the general population drawn from the TCI manual. We found males with ASD with significant higher scores on Harm Avoidance, and significant lower scores on Novelty Seeking, Reward Dependence, Self-Directedness, and Cooperativeness compared to the comparison group. In this study, we confirmed and strengthened earlier general group matching findings from our 2012 study and from studies in Sweden and the Netherlands with the score pattern for temperament and character we found in males with ASD by individual case matching. In our study, we discussed the negative as well as the positive aspects of the scores on the TCI, whereas previous studies mainly focused on the negative aspects of these scores (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002).

In Chapter 5, we explored the atypical social interaction styles (SISs), for the first time described by Wing and Gould (1979), of adult males with ASD with or without PD (traits) ($n = 30$) compared to males with a PD without ASD ($n = 30$), and males without

ASD and without a PD ($n = 30$), aged 18 to 65 years, without intellectual disability, and we explored the association between SISs and DSM-5 PD traits (American Psychiatric Association 2013) for the ASD group and the PD group. We found a clear distinction in distribution of SISs between the ASD group and the PD group (88% vs 27%), and between the ASD group and the nonpatient group (88% vs 0%). The active-but-odd, passive, and stilted SISs were more allocated to the ASD group than to the PD group. The neutral SIS was more allocated to the PD group, and the participants in the general population group were solely classified with a neutral SIS. Our results suggested atypicalities in SIS is more common in males with ASD than in males with PD. We found the active-but-odd SIS to be negatively associated with schizoid PD traits, and the stilted SIS to be negatively associated with dependent and borderline PD traits. SISs were found to be related to educational levels as having an active-but-odd SIS was related to relatively lower educational levels, and having a stilted SIS was related to higher educational levels.

9.2.3 Psychotherapy for adults with ASD and comorbid PD

In Chapter 6, we outlined a case example of an adult male with ASD and comorbid depressive disorder, social anxiety disorder, and PD not otherwise specified with avoidant PD traits. The ST approach was exemplified as a treatment possibility for the comorbid PD. ST was confronting, yet in the end, the client realized that it brought him new functional core beliefs about himself, better self-esteem, less anxious feelings and thoughts, and more skills to manage social interaction. This case example showed ST to be a potential effective treatment for PD in people with ASD. However, to test whether this is actually the case or just specific for this case, a ST effectiveness study is needed.

In Chapter 7, we therefore presented a protocol for a specific ST program aiming to investigate the effectiveness of ST for PDs in adults with both ASD and PD. In Chapter 8, we investigated the effectiveness of this ST program for adults with both ASD and PD. We used a multiple case series design. We included 12 participants (nine males, three females), aged 19-62 years, without intellectual disability, all diagnosed with ASD and one or more PDs. After a screening of two sessions for eligibility, participants started with a baseline period and supportive sessions of 10 weeks, followed by 5 weekly exploration sessions, 30 weekly ST sessions (with 15 cognitive behavioral and 15 experiential sessions), and 10 monthly follow-up sessions. We examined if dysfunctional core beliefs, dysfunctional schema modes, PD traits, general mental health symptoms, and DSM-IV Axis-I mental disorders decreased, and if functional schema modes and social responsiveness increased. The significant results with medium to large effect sizes showed a decrease of dysfunctional core beliefs, PD traits, and general mental health symptoms, and an increase of the functional modes and social responsiveness remaining stable at follow-up. We also

examined if order in starting with cognitive behavioral or experiential techniques, and which one of these two techniques would lead to a better outcome. For order nor for superiority for one of these two techniques we found no evidence for a better outcome. This first study exploring ST for treating personality pathology in adult males and females with ASD suggests that ST is indeed a promising intervention for this specific population.

9.3 Methodological considerations

9.3.1 Study designs

In this thesis, we used different types of research methods: cross-sectional design (Chapters 2 and 4), review and meta-analysis (Chapter 3), experimental design (Chapter 5), and a multiple case series design (Chapter 8).

For the included studies, we recruited all participants with ASD and those with PD from three sources: (1) Sarr Autism Rotterdam, Parnassia Psychiatric Institute, the Netherlands; (2) different general mental health outpatient clinics Rotterdam, Parnassia Psychiatric Institute, the Netherlands; and (3) Erasmus MC, Department of Psychiatry, Rotterdam, the Netherlands. Nonpatient participants were recruited from the general population by advertisements and flyers. For one study (Chapter 4) a comparison group of nonpatient participants was drawn from a manual. Participants of the NIDA study (Chapter 2) also participated in the SIS study (Chapter 5).

In the TCI study (Chapter 4), the data were collected in 2007-2010, and first published in the Dutch *Journal of Psychiatry* with a national readership (Vuijk et al. 2012). Because of the growing interest in this topic, we aimed to make our findings available to a larger and international audience. Moreover, this ensures that the reported findings can also serve possible purposes of future reviews and meta-analyses. So the present study has been a revision and an update, and data differed from data published in 2012. In Chapter 4, we individually matched our ASD group as closely as possible to a (new) norm group (selected from the norm group of the TCI manual; Duijsens & Spinhoven 2004). Moreover, we used a stronger design of individual case matching compared with our study of 2012 (Vuijk et al. 2021) and previous studies (Anckarsäter et al. 2006; Sizoo et al. 2009; Söderström et al. 2002) which employed general group matching. In our TCI study, we observed low comorbidity of co-occurring conditions in our ASD group compared to high comorbidity to be expected in adults with ASD (Lever & Geurts 2016; Mannion & Leader 2013; Hossein et al. 2020). In the period of 2007-2010, at Sarr Autism Rotterdam, in ASD assessment describing mental health pathology was more prominent than classifying the DSM-disorders, besides ASD, explaining the difference in comorbidity rates between the literature so far and our TCI study.

In four of the included studies (Chapters 2, 4, 5, and 8), self-report questionnaires and/or in-person interviews were used. For a valid interpretation of the findings obtained with these instruments, one needs to assume a certain level of self-insight of the person assessed. In contrast to the general opinion of low self-insight in people with ASD, a study examining self-insight by comparing self-reports and parent-reports found adequate levels of self-insight in people with ASD compared to non-ASD individuals (Schriber et al. 2014). Also a study examining the importance of self-report of adolescents with ASD and at least average cognitive abilities showed the validity of self-reports (Keith et al. 2019). And finally, a study testing the validity and reliability of the *NEO-Personality Inventory-Revised* (NEO-PI-R; Costa & McCrae 1992) administered to adults with ASD concluded self-reports to be validly and reliably used by adults with ASD (Hesselmark et al. 2015). We, therefore, considered in-person interviews and personality measures in the studies for this thesis as appropriate to use.

9.3.2 Statistical analysis

For two of the included studies (Chapters 2 and 8), some further considerations and explanations regarding the statistical analysis than already discussed in these chapters can be identified.

An important analysis in studying psychometric properties of any new diagnostic instrument is the evaluation of the incremental validity. To establish that a new instrument is required, it is needed to show that using an older instrument (the ADOS-2 in our NIDA study; Chapter 2) results in poorer diagnostic accuracy than using the old instrument plus the new instrument (the ADOS-2 plus NIDA in our NIDA study; Chapter 2). For analyzing the incremental validity of an instrument the (binary) logistic regression would be the most appropriate. The NIDA is not an instrument with dimensional scoring, but with categorical scoring: ‘yes’ or ‘no’ DSM-5 ASD classification following the DSM-5 ASD criteria algorithm. We entered the ‘yes’ or ‘no’ ASD variables into the logistic regression in two steps with the ADOS-2 entered in the first step, and the ADOS-2 and the NIDA simultaneously entered in the second step. However, estimation failed, and no results could be presented. This was due to the already high specificities and sensitivities observed for both instruments. To solve this issue, a larger sample is needed, which would be a recommendation for future research. So, we have not used the aforementioned optimal method to test the incremental validity. Therefore, we have solved this issue by adding the sensitivity and specificity as part of the convergent validity statistics for the NIDA and the ADOS-2 simultaneously. The sensitivity and specificity scores of both instruments showed no incremental validity of the NIDA over the ADOS-2 and the NIDA simultaneously. The instruments can be seen as psychodiagnostic alternatives, both showing good sensitivity and specificity. Further, in our NIDA study (Chapter

2) interrater agreement was examined by calculating Krippendorff’s alpha values (Hayes & Krippendorff 2007), suitable when evaluating interrater agreement if different pairs of raters and/or the same rater with different other raters are used. The choice for an addition of calculations of Cohen’s kappa values (Cohen 1960) was to allow comparison of interrater agreement across studies in future studies/meta-analyses.

As already discussed in Chapter 8, for our ST study, we intended to use a multiple baseline case series design in line to what we preregistered (see Chapter 7). However, due to a misunderstanding we did offer an equal baseline length instead. By offering this equal baseline length of 10 weeks to all participants, we could not examine the multiple baseline length. The change in design into a multiple case series design especially influenced the possibility to draw causal conclusions from our primary outcome analysis because the evidence that occurrence of change as a result of the intervention instead of time is less strong.

9.4 Strengths and limitations

In each chapter, the strengths and limitations of each study are discussed. In here, the more general strengths and limitations are discussed.

‘People with autism spend most of their lives as adults yet, by far, most of the literature relating to autism has reported on research and practice with children’ (Morgan, 1996, p.1). Research dedicated to adults with ASD is growing, but still in its infancy. Research of diagnostic assessment of ASD in adults is scarce; research of personality (pathology) of adults with ASD is scarce; and research of treatment interventions for adults with ASD is scarce. The research topics in this thesis are, therefore, of importance, and were broad-ranging from diagnostic assessment, personality (pathology) to psychotherapy in adults with ASD aiming to contribute to the enhancement of knowledge of these topics in adults with ASD.

The studies in this thesis are not only focusing on ASD in adults, but also on personality (pathology). As far as we know, our studies distinguished from most other studies with adults with ASD in their PD comorbidity, and in their use of adults with PD as a comparison group: The studies in Chapters 2, 5, and 8 examining psychodiagnostic assessment of ASD, SIS-PD associations, and psychotherapeutic interventions included participants with ASD and comorbid PD (Chapters 2, 5, and 8) as well as participants with PD without ASD (Chapters 2 and 5).

In the studies in which participants are included (Chapters 2, 4, 5, and 8), the ASD diagnosis of the ASD participants was based on a multidisciplinary ASD diagnostic assessment including an in-person interview, interaction with the adult, observation of the adult, and an interview with the adult’s childhood caregiver or someone

who knew the adults very well in childhood when available, recommended by both the Dutch (Kan et al. 2013) and international guidelines on ASD in adults (NCCMH 2012). Thereby, the PDs in the ASD participants as well as in the PD participants were assessed with the Dutch version of the SCID-II (First et al. 1997; Dutch version: Weertman et al. 2000), SCID-5-PD (First et al. 2016; Dutch version: Arntz et al. 2017), or psychological-psychiatric assessment in the past, and thoroughly checked in the screening procedure of the studies. This has led to fairly clearly defined groups of participants and solidly based diagnoses.

The participants with ASD in four of the five studies (Chapters 2, 4, 5, and 8) were selected on their overt ASD presentations without too much camouflaging their social disability. We tried to exclude as much as possible the people who are not representing the 'prototype' of ASD in line with a recent proposal of Mottron (2021) to focus on a clearly distinguished ASD population. 'Focusing research on prototypical individuals must result in populations that favor the production of knowledge (Mottron 2021, p. 6).

In most of our studies (Chapters 2, 4, and 5), there was an exclusive inclusion of males with ASD, in two of them (Chapters 3 and 8) there was a small inclusion of females with ASD, and in none of the studies individuals with an intellectual disability were included. All participants were Caucasian. We mainly chose males with ASD for two reasons: (1) the availability of males (with a general male-to-female prevalence of 3.4:1; Wilson et al. 2016), and (2) to limit heterogeneity affected by sex differences (Loomes et al. 2017; Zhang et al. 2020). We chose males without intellectual disability to limit heterogeneity affected by intellectual functioning (Matson et al. 2008; Miot et al. 2019; Tureck et al. 2014). Thereby, in these studies (except for the ST study), the low mental health comorbidity prevalence in adults with ASD was not in line with the view on mental health comorbidity in literature, ranging from 59% suffering from mental disorders and symptoms to 79% meeting criteria for a mental disorder at least once in their lives (Buck et al. 2014; Croen et al. 2015; Kentrou et al. 2021; Lever & Geurts 2016). So the inclusion of Caucasian adults with ASD with low psychiatric comorbidity, without intellectual disability, and of the male sex, as just mentioned, resulted in a less heterogeneous group of adults with ASD limiting the generalizability to every adult with ASD. In the SIS study (Chapter 5), the small number of adults with ASD (and comorbid PD) as well as adults with PD allocated to the different SISs might have reduced the generalizability of the findings. Beside in all our studies, the intelligence of the participants ranged from average to high, so our results cannot be generalized to adults with ASD and an intellectual disability.

In the ST study (Chapter 8), the already discussed methodological limitation of a change in design may have affected the results. Visual inspection of our primary outcome, the individual averaged scores specifying the credibility of dysfunctional

core beliefs, showed no important changes (no increase, no decrease) in the baseline period and the supportive sessions. After careful deliberation of this inspection, we decided to change the multiple baseline design into a multiple case series design: the results of our primary outcome can but should be interpreted with caution.

Considering the strengths and limitations, the studies of this thesis may be possible new steps in (1) the use of an ASD assessment instrument in adults following the DSM-5 algorithm for diagnosing the ASD classification, (2) the growing knowledge and understanding of the personality (pathology), the SISs and their associations with PDs in adults with ASD, and (3) the development of treatment options of PD in adults with ASD.

9.5 Clinical relevance

The studies included in this thesis may provide useful information for clinical practice concerning ASD assessment in adult males, personality (pathology) of males with ASD, and psychotherapy for adult males and females with ASD and comorbid PD. First, our results show that the NIDA is promising to use as an ASD assessment instrument for adult males without intellectual disability suspicious for ASD (Chapter 2). Sensitivity and specificity results are considered to be very good. Even a comorbid PD did not affect the results on the NIDA whereas administering the NIDA to adult males with PD only leads to significant lower scores than to adult males with ASD (and a possible comorbid PD). Our results show that the majority of adult males with ASD can be correctly diagnosed with ASD by assessing them to the NIDA whereas adult males without ASD and adult males with PD correctly would not qualify for an ASD diagnosis according to the NIDA. These results indicate that the NIDA can be useful in clinical practice, especially in an ASD assessment of adult males with overt ASD characteristics.

Second, our results show that personality pathology and PDs in adult males (and females) with ASD are a serious comorbidity (Chapters 3, 4 and 5), relevant to know and to consider for adequate assessment for adults suspicious for ASD, for effective and individualized interventions and treatment plans, for establishing and maintaining a constructive and effective therapeutic alliance, and for understanding human behavior and development (Kanai & Rees 2011). When assessing an individual for the symptoms of ASD, the healthcare professional should consider the option of personality pathology, PDs, as well as personality strengths for an appropriate and comprehensive picture of the person with possible ASD. Based on our TCI study (Chapter 4), for a first screening of personality (pathology), we recommend the use of the TCI as this instrument maps both personality pathology as well as personality strengths. By focusing on the (pathological) temperament and character dimensions,

as we discussed in Chapter 4, and despite the existing stereotypical stigmas and biases related to ASD (Butler & Gillis 2011; Morrison et al. 2019; Gillespie-Lynch et al. 2021), this can hopefully contribute to an already improving attitude towards individuals with ASD (White et al. 2019). It has already been shown that disclosing an ASD diagnosis improved first impressions of adults with ASD without intellectual disability (Sasson & Morrison 2019), with positive effects on social acceptance (Thompon-Hodgetts et al. 2020), and a recent study on the effects of PD diagnosis disclosure in general public suggested less negative responding to PD behavior (O'Connor & Murphy 2021). In psychotherapy, in extension of our ST study findings (see Chapters 6 and 8), the healthcare professional not only needs to recognize the autism-specific way of thinking (Gaus 2019), but also needs to consider social interactional issues that can arise from possible personality pathology and PDs (Bender 2005; Colli & Ferri 2015; Schenk et al. 2021) for an adequate therapeutic alliance, therapist empathy, and responsiveness (Kramer et al. 2020). To fully understand ASD and its heterogeneity, we must at least also consider someone's personality and its possible pathology.

Third, ST is proven to be an evidence-based therapy for PDs in general (Bamelis et al. 2014; Giesen-Bloo et al. 2006), and also in special populations like older adults with PD (Khasho et al. 2019; Videler et al. 2018). ST recently has been rated as a positively experienced therapy by individuals with a borderline PD (Tan et al. 2018). And by now, ST could be a well considered treatment indication for PDs in adult males and females with ASD and comorbid PD because the results of our ST study (Chapter 8) showed effectiveness in treating personality pathology in case of ASD-PD comorbidity. In our case example (Chapter 6), ST is experienced as positive by the person with ASD and comorbid PD traits. ST differs not really for people with ASD compared to people with other mental disorders, considering some modifications like incorporating autism-driven coping responses, and the autism-specific needs alongside the core emotional needs central to ST (Bulluss 2019).

9.6 Recommendations for future research

As aforementioned, the diversity of our included study samples were limited and, therefore, in future studies, we recommend the inclusion of a more diverse and broader population including (more) females and individuals from racially/ethnically diverse backgrounds for the generalizability of findings.

More research is needed to strengthen the validated psychometric properties of the NIDA (Chapter 2) in adults with ASD compared to adults with comparable difficulties in social interaction, e.g., adults with social anxiety disorder and avoidant PD, or mixed neuropsychiatric challenges. Along with these extensions, not only the

in-person current functioning part of the interview should be studied but also the past functioning part. Both parts should be administered to the person suspicious for an ASD diagnosis as well as their informants like parents and partner.

Personality (pathology) in people with ASD is more and more topic of diagnostic assessment and treatment interventions in clinical practice. Studying personality pathology as well as personality strengths in people with ASD is quite a new phenomenon, and it is still in its infancy: studying ASD characteristics in people with PD is even more a rarity. Our studies reviewed personality (pathology) in adult males and females with ASD (Chapter 3), explored temperament and character dimensions in adult males with ASD (Chapter 4), and explored autism-specific atypical SISs and its possible associations with DSM-5 PD traits in adult males with ASD, and in males with PD without ASD (Chapter 5). For many years, personality (pathology) and especially temperament have also been topic of research in infants, toddlers, and children with ASD. Review studies (Chetcuti et al. 2021; Mallise et al. 2020) determining temperament dimensions associated with ASD in childhood showed a challenging temperament with higher negative affect, less extraversion, and less effortful control than typically developing children. A next step would be to discover similarities and differences in temperament, character, and personality (pathology) between children, adolescents, and adults with ASD. In this way, we could discover the stability or change of these constructs over time in people with ASD. Despite more and more studies examining personality (pathology) in individuals with ASD including our studies (Chapters 3, 4 and 5) finding associations between ASD and personality (pathology), only a small proportion of studies examined causality with respect to ASD and personality (pathology), like early temperament as an endophenotype for ASD (Garon et al. 2016), ASD and personality dimensions both influenced by phenotypic correlation related to common genetic effects (Kerekes et al. 2013), and a suggested sharing of common genetic and environmental etiological factors between ASD characteristics and personality dimensions (Picardi et al. 2015). Studies examining the relation between ASD, personality and PDs are needed to identify the extent and nature of cause and effect.

More research is needed to examine and develop effective treatment interventions focused on adults with ASD and comorbid PD to influence the personality pathology: as far as we know, our ST study showed positive results (Chapter 8). The results should be replicated in a larger and independent population in a randomized clinical trial (RCT). We found a few participants of the ST study more or less benefitting the ST interventions. As we have discussed in Chapter 7, the reasons for benefitting or not benefitting from ST in adults with ASD and comorbid PD need a further investigation as for now we do not have a good explanation for the individual differences in benefitting or not benefitting from ST. Until now only a small number of PD therapies like ST (Oshima et al. 2018; 2021), mentalization-based treatment (MBT; Thevenet

et al. 2018), and dialectical behavior therapy (DBT; Cornwall et al. 2021; Hartmann et al. 2012; Huntjens et al. 2020) are being or have been studied in children and adults with ASD without PD, not targeting PDs, but mental conditions (Oshima et al. 2018; 2021), theory-of-mind impairments (Thevenet et al. 2018), and distress, emotion regulation, self-destructive behavior, and suicidality (Cornwall et al. 2021; Hartmann et al. 2012; Huntjens et al. 2020). Treatment interventions like ST, MBT, DBT need to be future topic of research to investigate which PD treatment will be most appropriate and (cost-) effective for influencing personality pathology in adults with ASD and comorbid PD.

9.7 Concluding remarks

There is overlap between ASD and personality pathology and PDs, as suggested by several previous studies (Dudas et al. 2017; Gadelkarim et al. 2021, Lugnegård et al. 2012). The results of the studies in this thesis showed that ASD, temperament, character, personality pathology, and PD overlap *and* differ in phenotypic presentation (Chapters 3, 4, and 5; see also May et al. 2021). For the difference in phenotypic presentation, for example, it became clear from the results of our study examining the psychometric properties of the NIDA (Chapter 2) that people with PD hardly displayed DSM-5 ASD symptoms when being assessed with the NIDA. These findings are encouraging, because especially in clinical practice, the differential diagnosis between ASD and PD seems difficult because of the suggested overlap and similarities. The results of our meta-analyses of PD prevalence in males with ASD (Chapter 3), showing PDs to be a serious psychiatric comorbidity in individuals with ASD prompted us to initiate an exploratory study examining possible relationships between ASD SISs and DSM-5 PD traits (Chapter 5) as well as to initiate a study investigating whether treatment of personality pathology in people with ASD is possible (Chapters 7 and 8). Our SIS study (Chapter 5) showed that the atypical SISs were most found in people with ASD, except for the active-but-odd SIS, which was also found in people with PD. This study may be a starting point for further reflection on the relationship between atypical SIS and PDs. In the ST study (Chapters 7 and 8), we have seen a representation of the personality pathology in the ASD participants, as demonstrated in our review study (Chapter 3). The results of our ST study showed promising results for the future of PD treatment in people with ASD and comorbid PD.

9.8 Key findings

- An important part of the *Dutch interview for Diagnostic Assessment of Autism spectrum disorder in adults* (NIDA; Vuijk 2016) shows preliminary indications of its psychometric usefulness in adult males without intellectual disability (Chapter 2).
- Autism spectrum disorder (ASD) is associated with a temperament characterized by introversion, rigidity, passive-dependence with low Novelty Seeking, high Harm Avoidance, low Reward Dependence and high Persistence, and with a risk for deficits in character development with low Self-Directedness, low Cooperativeness, and high Self-Transcendence. (Chapters 3 and 4).
- ASD traits are positively correlated with Neuroticism, and negatively correlated with Extraversion, Openness to Experience, Agreeableness, and Conscientiousness (Chapter 3).
- ASD is positively correlated with paranoid, schizoid, schizotypal, avoidant, and obsessive-compulsive personality disorders (PDs) (Chapter 3).
- For a complete picture of an individual with ASD, for implementation of the most effective treatment interventions for, and therapeutic bonding with adults with ASD, we advise to consider temperament, character, comorbid personality pathology, and PDs (Chapters 3 and 4).
- There is a clear distinction in distribution of social interaction styles (SISs) between adult males with ASD, adult males with a PD, and nonpatient males. Atypical SISs are represented more often in adult males with ASD than in adult males with a PD, whereas the typical style is represented more often in males with PD, and it is the sole SIS represented in nonpatient males. The manifestation of atypicalities in SIS is far more characteristic of individuals with ASD than of individuals with PD (Chapter 5).
- The active-but-odd SIS is negatively associated with schizoid PD traits, and the stilted SIS is negatively associated with dependent and borderline PD traits in adults with ASD (Chapter 5).
- SIS in adults with ASD is related to educational level: the active-but-odd SIS is associated with relatively lower education, and the stilted SIS is associated with relatively higher education (Chapter 5).
- ST seems effective in treating personality pathology in adults with ASD and comorbid PD (Chapter 8).

Summary

Autism spectrum disorder (ASD) in adults has been an important clinical entity since the 1990s. The attention to and knowledge of the disorder in adults is growing. However, the knowledge of ASD in adults is still limited, and requires more scientific research. The studies in this thesis, all focused on adults with ASD (but mainly males), contribute to more knowledge about psychodiagnostic assessment, personality (pathology), and psychotherapy. The present thesis consists of three parts. The first part, Chapter 2, focuses on diagnostic assessment. The second part consists of Chapters 3, 4, and 5, which provide insight into personality (pathology) of adults with ASD, and possible correlations between personality pathology and ASD-specific social interaction styles (SISs). Finally, the third section consists of three Chapters (6, 7, and 8) focused on psychotherapy for personality disorders (PDs).

Chapter 1 introduces ASD in general, adults with ASD in particular, and discusses the background of the studies in this thesis. ASD is a neurobiological developmental disorder with a history dating back to the 1940s. The disorder was originally described as early childhood autism in 1943 by Leo Kanner, an Austrian-American psychiatrist. In his practice, Kanner observed children whose behavior he described as extremely introvert with a tremendous lack of social understanding and interaction with others. Hans Asperger, an Austrian psychiatrist, also observed children with a lack of social skills and social understanding in 1944, and he was the first to speak of an autistic character of the parents of these children. However, it was not until the late 1980s that more attention in clinical practice arose for ASD in adulthood. In the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition* (DSM-IV; American Psychiatric Association 2000) ASD was classified as autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise defined (PDD-NOS). The *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* (DSM-5; American Psychiatric Association 2013), published in 2013, ASD is classified as ASD. The disorder is not only a distinct DSM category: ASD is also heterogeneous and dimensional: heterogeneous for its clinical and neurobiological diversity, and dimensional for its disorder conditions and the way of being and living with ASD. A 1% prevalence of ASD is estimated in the general population. The male-female ratio in ASD as well as the male-female differences in ASD presentation have been subject of debate in recent years. The cause of ASD is not yet fully understood, but genes influenced by environmental factors seem to be an important factor in causing ASD. For many adults with ASD, living with ASD and comorbid problems can be challenging. There is an urgent need for adequate diagnostic assessment, psychotherapy, and counseling tailored made for the individual with ASD and their challenges. In clinical practice, diagnostic assessment for adults suspicious for

ASD is still far from ideal, and is a challenging task for the professional caused by, among others: (1) a small number of ASD diagnostic assessment instruments and its limited or lacking psychometric validity, (2) the camouflaging of social interaction disabilities, and (3) difficulty in differentiating between comorbidity of and overlap with other (developmental) disorders. Treatment of adults with ASD and comorbid disorders is still in its infancy. Cognitive behavioral therapy appears to be especially effective for anxiety and mood disorders in adults with ASD. Our knowledge of personality (pathology) of children, adolescents, and adults with ASD is more and more growing. By knowing someone's personality (pathology) we can create a more comprehensive picture of the person with ASD, as well as it can be an indication for psychotherapy focused on the specific personality pathology.

In **Chapter 2** we examined the psychometric properties of the in-person current functioning part of the *Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults* (NIDA; Vuijk 2016). Ninety males, aged 18 to 65 years, divided into three groups (ASD, PD, and non-clinical individuals) participated in the study. We found a strong inter-rater reliability, a good congruent validity with good sensitivity and specificity of the NIDA compared to the clinical diagnosis of ASD and the *Autism Diagnostic Observation Schedule Second Edition* (ADOS-2; Lord et al. 2012), and a strong concurrent criterion-related validity. The results suggest the in-person current functioning part of the NIDA to be psychometrically sound.

In **Chapter 3** using a systematic literature review and meta-analysis, we examined temperament, character, personality pathology, and PDs in adults with ASD across 15 studies, including 992 participants, aged 16 to 87 years (male 72%, female 28%). We found a positive association between ASD and Neuroticism, and a negative association with Extraversion, Openness to Experience, Altruism, and Conscientiousness. Adults with ASD have a temperament described as introverted, rigid, and passive-dependent. Their character is characterized by low Self-Directedness, challenges in Cooperativeness, and a high Self-Transcendence. Adults with ASD may be afflicted with PDs, specifically the paranoid, schizoid, schizotypal, avoidant, and compulsive PDs.

In **Chapter 4** we examined temperament and character dimensions in 66 adult males with ASD, aged 18 to 63 years. This study using individual group matching reanalyzed the results of a previous study from 2012 which was based on general group matching. The *Temperament and Character Inventory* (TCI; Cloninger et al. 1993) was administered to the participants. Compared to the norm group individuals drawn from the TCI manual, we found that males with ASD scored significantly lower on Novelty Seeking, Reward Dependence, Self-Directedness, and Cooperativeness, and significantly higher on Harm Avoidance. The results are consistent with those of the 2012 study as well as previous TCI studies with adults with ASD in the Netherlands

and Sweden. In the discussion section of the current study, in contrast to previous studies, we discussed the positive interpretation possibility of the negative outcomes on the temperament and character dimensions.

In **Chapter 5**, in an explorative study of 90 males aged 18 to 65 years, divided into three groups (ASD, PD, and nonpatient participants), we explored the presence of their social interaction style (SIS), and we examined the associations between atypical SISs and DMS-5 PD traits per SIS. We found the passive and stilted SIS to be significantly more prevalent in the ASD group, the typical SIS to be significantly more prevalent in the PD group and the nonpatient group, and the active-but-odd SIS to be non-significantly different between the ASD group and the PD group. The active-but-odd SIS was negatively associated with schizoid PD traits, and the stilted SIS was negatively associated with dependent and borderline PD traits. SIS is related to educational level: lower educational levels for the active-but-odd SIS and higher educational levels for the stilted SIS. This study contributes to a better understanding of the interactional differences among adults with ASD as well as compared to adults with PDs.

Chapter 6 presents a case study of an adult male with ASD and personality pathology. He was treated with Schema Therapy (ST). The psychotherapist is given the practical 'dos and don'ts' when ST is indicated to adults with ASD and comorbid personality pathology. The core techniques of ST, such as imaginary rescripting and chair dialogue, are exemplified. The treatment resulted in new functional core beliefs, better self-esteem, less anxious feelings and thoughts, and more skills to manage social interaction.

In **Chapter 7** we described the protocol of our ST program for adults with both ASD and PD aiming to investigate whether ST with cognitive behavioral and experiential techniques will be effective for adults with both ASD and PD.

In **Chapter 8** we examined the effectiveness of ST (following the protocol presented in Chapter 7) for adults with ASD and comorbid PD. The study with a multiple case series design consisted of 12 participants (aged 19 to 62 years; nine males, three females). After a baseline period with supportive sessions for 10 weeks, participants received treatment in 35 weekly sessions. The treatment period included five sessions of exploration of dysfunctional core beliefs, schema modes, current and past functioning, and general mental health symptoms, 15 sessions of cognitive behavioral techniques, and 15 sessions of experiential techniques. Finally, they were offered one follow-up session per month during 10 months. Using a mixed model analysis, we found dysfunctional core beliefs, DSM-IV PD traits, and general mental health symptoms to be significantly decreased, and functional schema modes and social interaction and communication to be significantly improved. The dysfunctional schema modes and the general DSM-IV Axis-I mental disorders including anxiety and mood disorders showed no significant improvement. Finally, we found both

cognitive behavioral and experiential techniques to be equally effective, and the order in which these techniques were offered showed no different result. This study suggests that ST may be an effective treatment for adults with ASD and comorbid PD.

Finally, **Chapter 9** presents the main findings of the studies in this thesis. Methodological considerations, clinical relevance, and recommendations for future research were discussed. One of the strengths of the studies is the inclusion of adults with ASD, also afflicted with personality pathology/PD. In two studies (Chapters 2 and 5), they were compared to adults with PD, relevant for clinical practice, as in recent years the demand for diagnostic assessment (overlap and differential diagnosis) and treatment options for (the combination of) ASD and PD appears to be increasing. In addition, the ASD classification was diagnosed according to the ASD guidelines for adults. Many participants showed an overt ASD presentation and characteristics, resulting in clearly defined groups. The limitations of the studies are the majority of the participants to be males with a normal intelligence, limiting the generalizability of the results to females and adults with ASD and intellectual disability. In addition, in two studies (Chapters 2 and 5), a large number of participants with ASD was not afflicted with a PD, so interpreting the results for all adults with ASD and comorbid PD should be with caution. The results are relevant for clinical practice: (1) the NIDA is an instrument, following the classification criteria of the DSM-5, that can be considered reliable and valid for diagnostic assessment of ASD in adult males. When NIDA is administered to males with a PD, the results showed them to be scoring correctly negative for an ASD classification; (2) personality pathology can be a serious comorbidity in adults with ASD, which should be considered in diagnostic assessment, psychotherapy, and social interaction. For the first time, as far as we know, the SISs in males with ASD have been explored, and three different negative associations between atypical SISs and DSM-5 PD traits as well as associations between atypical SISs and educational level have been identified; and (3) for the psychotherapist, ST has shown to be an effective therapy for treating adults with ASD and a PD. Future research concerning the topics of these studies should include males and females in equal numbers. Longitudinal research studying personality (pathology) in children, adolescents, and adults with ASD is needed to gain insight into the course, stability, and change in these concepts over time. Research in personality (pathology) and ASD, is, like in the studies of this thesis, mainly correlational; future research should focus on the causal relationship between ASD and personality (pathology). Finally, future research should focus on which of the PD treatments will be most effective for treating personality pathology in adults with ASD and comorbid PD.

Samenvatting (Summary in Dutch)

Autismespectrumstoornis (ASS) bij volwassenen is sinds de jaren negentig van de vorige eeuw een belangrijke klinische entiteit: er is een groeiende aandacht voor en kennis over ASS bij volwassenen. De kennis die we hebben van deze stoornis bij volwassenen is echter nog beperkt en vraagt om meer wetenschappelijk onderzoek. De studies in dit proefschrift, alle gericht op volwassenen met ASS, leveren een bijdrage aan meer kennis over psychodiagnostiek, persoonlijkheid(spathologie) en psychotherapie. Het huidige proefschrift bestaat uit drie delen. In het eerste gedeelte, hoofdstuk 2, staat de psychodiagnostiek centraal. Het tweede gedeelte bestaat uit de hoofdstukken 3, 4 en 5 en hierin wordt inzicht gegeven in de persoonlijkheid(spathologie) van volwassenen met ASS, en een mogelijke samenhang tussen persoonlijkheidspathologie en ASS-specifieke sociale interactiestijlen (SISen). Het derde gedeelte, ten slotte, bestaat uit de hoofdstukken 6, 7 en 8 gericht op de psychotherapie voor persoonlijkheidspathologie.

Hoofdstuk 1 betreft een introductie van ASS in het algemeen, volwassenen met ASS in het bijzonder en tot het bespreken van de achtergrond van de studies in dit proefschrift. ASS is een neurobiologische ontwikkelingsstoornis met inmiddels een geschiedenis die teruggaat tot de jaren 40 van de vorige eeuw. De stoornis, voor het eerst vroegkinderlijk autisme genoemd, wordt in 1943 voor het eerst beschreven door Leo Kanner, een Oostenrijks-Amerikaans psychiater, die in zijn praktijk kinderen ontmoette bij wie hij hun gedrag omschreef als extreem in zichzelf gekeerd met een enorm gebrek aan sociaal inzicht en omgang met de ander. Hans Asperger, een Oostenrijks psychiater, die in 1944 eveneens kinderen met een gebrek aan sociale vaardigheden en sociaal begrip ontmoette, was de eerste die sprak van het autistische karakter van de ouders van deze kinderen. Het duurde vervolgens nog tot eind jaren 80 van de vorige eeuw dat er in de klinische praktijk meer aandacht ontstond voor ASS op volwassen leeftijd. In de vierde editie van de *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; American Psychiatric Association 2000) spreken we van de autistische stoornis, stoornis van Asperger en de pervasieve ontwikkelingsstoornis niet anderszins omschreven (PDD-NOS). Met de komst van de vijfde editie van *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association 2013) in 2013 spreken we van ASS. De stoornis wordt niet alleen gezien als een DSM-categorie: ASS is een heterogene en dimensionele stoornis: heterogeen in verschijningsvorm en neurobiologische diversiteit, dimensioneel in stoornis en manier van zijn en leven. De stoornis komt bij 1% van de algemene bevolking voor. De man-vrouw verhouding in het voorkomen van ASS alsook het man-vrouw verschil in de uitingsvorm van ASS zijn de laatste jaren onderwerp van discussie. De oorzaak van ASS is nog niet bekend, maar erfelijkheid lijkt een belangrijke rol onder invloed

van omgevingsfactoren te spelen. Voor veel volwassenen met ASS kan het leven met ASS en bijkomende problemen een zware opgave zijn. Hulpverlening in de vorm van adequate psychodiagnostiek en op de individu en diens uitdagingen afgestemde psychotherapie en begeleiding is dan ook zeer dringend nodig. In de klinische praktijk is psychodiagnostisch onderzoek bij volwassenen met een vermoeden van ASS nog verre van ideaal en het is een ingewikkelde activiteit: (1) er is slechts een beperkt aantal psychodiagnostische instrumenten om ASS vast te stellen en de psychometrische validiteit ervan is beperkt of ontbreekt, (2) het camoufleren van de contactuele beperkingen en (3) de raakvlakken met en afbakening van andere (ontwikkelings)stoornissen zorgen voor een complexe differentiaal diagnostische puzzel. Behandeling van volwassenen met ASS en bijkomende stoornissen staat nog in de kinderschoenen. Met name blijkt cognitieve gedragstherapie enig effect te hebben op met name angst- en stemmingsstoornissen bij volwassenen met ASS. We komen steeds meer te weten over de persoonlijkheid(spathologie) van zowel kinderen, jeugdigen als volwassenen met ASS. Met het kennen van de persoonlijkheid(spathologie) kunnen we meer rekening houden met de persoon met ASS alsook indien nodig de persoonlijkheidspathologie behandelen met een daarvoor geschikte psychotherapie.

In **hoofdstuk 2** onderzochten wij de psychometrische eigenschappen van het *Nederlands Interview ten behoeve van Diagnostiek Autismespectrumstoornis bij volwassenen* (NIDA; Vuijk 2016). Negentig mannen in de leeftijd van 18 tot 65 jaar, verdeeld over drie groepen (ASS, persoonlijkheidsstoornissen en niet-klinische personen) namen deel aan het onderzoek: van de NIDA werden de vragen over het huidige functioneren aan hen gesteld. Wij vonden een hoge interbeoordelaarsbetrouwbaarheid, een sterke congruente validiteit met goede sensitiviteit en specificiteit ten opzichte van de klinische diagnose ASS en het *Autisme Diagnostische Observatie Schema Tweede Editie* (ADOS-2; Lord et al. 2012) en een sterke concurrente criterium-gerelateerde validiteit. De resultaten suggereren dat het deel van de NIDA met betrekking tot de vragen over het huidige functioneren gesteld aan de onderzochte zelf psychometrisch valide is.

In **hoofdstuk 3** hebben we met een systematische literatuurstudie en een meta-analyse temperament, karakter, persoonlijkheidspathologie en persoonlijkheidsstoornissen bij volwassenen met ASS in kaart gebracht. We includeerden 15 studies met in totaal 992 deelnemers (72% mannen, 28% vrouwen), in leeftijd variërend van 16 tot 87 jaar. We vonden een positieve samenhang tussen ASS en negatieve emotionaliteit, en een negatieve samenhang met extraversie, openheid, altruïsme en consciëntieusheid. Volwassenen met ASS hebben een temperament dat omschreven kan worden als introvert, rigide en passief-afhankelijk. Het karakter kenmerkt zich door weinig zelfsturing, een moeite hebben met samenwerken en

inleven, en een mate van naïviteit en idealisme. Volwassenen met ASS kunnen behept zijn met persoonlijkheidsstoornissen en dan voornamelijk de paranoïde, schizoïde, schizotypische, vermijdende en dwangmatige persoonlijkheidsstoornissen.

In **hoofdstuk 4** hebben we temperament en karakter bij 66 volwassen mannen met ASS in de leeftijd van 18 tot 63 jaar onderzocht. Deze studie met individuele case matching heeft de resultaten van een eerdere studie uit 2012 gebaseerd op groepsmatching geheranalyseerd. De *Temperament en Karakter Vragenlijst* (TCI; Cloninger et al. 1993) werd door de deelnemers ingevuld. In vergelijking met de normgroep uit de Nederlandstalige handleiding van de TCI vonden we dat mannen met ASS significant lager scoren op prikkels zoeken, sociale gerichtheid, zelfsturing en coöperatief, en significant hoger scoren op leedvermijding. De resultaten komen overeen met die van de studie uit 2012 alsmede eerdere onderzoeken met de TCI bij volwassenen met ASS in Nederland en Zweden. In de discussie van de huidige studie hebben we in tegenstelling tot eerdere studies stil gestaan bij de positieve interpretatiemogelijkheid van de negatieve uitkomsten op de temperament en karakter dimensies.

In **hoofdstuk 5** hebben we in een exploratieve studie bij 90 mannen in de leeftijd van 18 tot 65 jaar, verdeeld over drie groepen (ASS, persoonlijkheidsstoornissen en niet-klinische deelnemers) hun sociale interactiestijl (SIS) in kaart gebracht en vervolgens gekeken of we per SIS een relatie met DSM-5 persoonlijkheidstrekken konden ontdekken. We vonden dat de passieve en formalistische SIS significant meer voorkwamen in de ASS-groep, de neurotypische SIS significant meer in de persoonlijkheidsstoornissen-groep en de niet-klinische groep, en het voorkomen van de actief-maar-vreemde SIS was niet-significant verschillend tussen de ASS-groep en de persoonlijkheidsstoornissen-groep. We vonden een negatieve associatie tussen de actief-maar-vreemde SIS en schizoïde persoonlijkheidstrekken en een negatieve associatie tussen de formalistische SIS en afhankelijke en borderline persoonlijkheidstrekken. We vonden een relatie tussen SIS en opleiding: lagere opleidingsniveaus bij de actief-maar-vreemde SIS en hogere opleidingsniveaus bij de formalistische SIS. Deze studie draagt bij aan een beter begrip van de interactionele verschillen van volwassenen met ASS onderling.

In **hoofdstuk 6** wordt een casus gepresenteerd van een man met ASS en persoonlijkheidspathologie. Hij werd behandeld met schematherapie. Het hoofdstuk geeft voor de psychotherapeut een praktisch zicht op waar je als therapeut rekening mee dient te houden als je schematherapie geeft aan volwassenen met ASS en comorbide persoonlijkheidspathologie. De voor schematherapie kenmerkende technieken als imaginaire rescripting en stoelendialoog worden uitgewerkt. Het eindresultaat in deze casus was nieuwe functionele kerngedachten, meer zelfwaardering, minder angstgevoelens en angstige gedachten en een toename van sociale vaardigheden.

In **hoofdstuk 7** wordt het protocol voor schematherapie voor volwassenen met ASS en een comorbide persoonlijkheidsstoornis weergegeven met als doel te onderzoeken of deze therapie met cognitief-gedragstherapeutische en experiëntiële technieken effectief is voor volwassenen met ASS en comorbide persoonlijkheidsstoornis.

In **hoofdstuk 8** onderzochten we de effectiviteit van schematherapie (volgens het protocol uit hoofdstuk 7) voor volwassenen met ASS en een comorbide persoonlijkheidsstoornis. De studie met een multiple case series design bestond uit 12 deelnemers (negen mannen en drie vrouwen) in de leeftijd van 19 tot 62 jaar. Na een baseline periode met ondersteunende sessies van 10 weken kregen de deelnemers een behandeling van 35 wekelijkse sessies waaronder vijf sessies exploratie van disfunctionele kerncognities, schema modi, huidig en vroeger functioneren, en psychische problemen, vervolgens 15 sessies met cognitief-gedragstherapeutische en 15 sessies met ervaringsgerichte technieken. Tot slot kregen zij nog één follow-up sessie per maand gedurende 10 maanden aangeboden. We vonden met een mixed model analyse, dat disfunctionele kerncognities, DSM-IV persoonlijkheidstrekken en psychische lijdensdruk significant verminderden, en dat de gezonde schema modi en de sociale interactie en communicatie significant verbeterden. Op de disfunctionele schema modi en de DSM-IV As I stoornissen waaronder angst- en stemmingsstoornissen zagen we geen significante verbetering. Tot slot bleek, dat zowel de cognitief-gedragstherapeutische als de ervaringsgerichte technieken even effectief waren en dat de volgorde van aanbieden van deze technieken geen verschil maakte. Deze studie suggereert dat schematherapie een effectieve behandeling voor volwassenen met ASS en comorbide persoonlijkheidsstoornis kan zijn.

In **hoofdstuk 9** zijn, tot slot, de belangrijkste bevindingen van de studies in dit proefschrift weergegeven. Methodologische overwegingen, klinische relevantie en aanbevelingen voor toekomstig onderzoek zijn besproken. Een van de sterke kanten van de studies is dat het volwassenen met ASS betrof bij wie ook sprake was van persoonlijkheidspathologie/persoonlijkheidsstoornis. In twee studies (Hoofdstuk 2 en 5) zijn zij ook vergeleken met volwassenen met een persoonlijkheidsstoornis, relevant voor de klinische praktijk, want de laatste jaren blijkt de vraag naar psychodiagnostiek (overlap en onderscheid) en mogelijkheden voor behandeling voor (de combinatie van) ASS en persoonlijkheidsstoornis steeds vaker gesteld te worden. Daarnaast is de ASS-classificatie bij alle deelnemers (in het verleden) gesteld volgens de richtlijn voor psychodiagnostiek van ASS bij volwassenen. Bij veel deelnemers was daarbij sprake van een duidelijke verschijningsvorm en presentatie van de ASS-kenmerken hetgeen zorgde voor goed onderscheidbare groepen. De beperkingen van de studies zijn dat het merendeel van de deelnemers mannen waren met een ten minste normale intelligentie. Dit beperkt de generaliseerbaarheid van de resultaten naar vrouwen en volwassenen met ASS en een verstandelijke beperking. Daarnaast was in twee studies (Hoofdstuk 2 en 5) bij een groot deel van

de deelnemers met ASS geen sprake van een persoonlijkheidsstoornis waardoor we de resultaten met voorzichtigheid dienen te interpreteren voor alle volwassenen met ASS en comorbide persoonlijkheidsstoornis. De resultaten zijn relevant voor de klinische praktijk: (1) met de NIDA heeft de psychodiagnosticus een instrument in handen waarmee conform de classificatie criteria van de DSM-5 betrouwbaar en valide bij mannen ASS overwogen kan worden. Daarbij is uit de resultaten gebleken dat bij afname van de NIDA bij mannen met een persoonlijkheidsstoornis zij correct negatief scoorden voor een ASS-classificatie; (2) persoonlijkheidspathologie kan een serieuze comorbiditeit zijn bij volwassenen met ASS waarmee rekening gehouden dient te worden in zowel de psychodiagnostiek, de psychotherapie als de sociale interactie. Voor het eerst, voor zover wij weten, zijn de SISEn bij mannen met ASS in kaart gebracht en vervolgens zijn drie negatieve associaties tussen atypische SISEn en DSM-5 persoonlijkheidstrekken alsmede associaties tussen atypische SISEn en opleidingsniveau vastgesteld; en (3) de psychotherapeut heeft met ST een therapie tot zijn beschikking die effectief is gebleken voor de behandeling van volwassenen met ASS en comorbide persoonlijkheidsstoornis. In toekomstig onderzoek met betrekking tot de onderwerpen van deze studies zouden de onderzoeksgroepen een evenwichtiger man-vrouw verhouding moeten hebben. Longitudinaal onderzoek naar persoonlijkheid(spathologie) bij zowel kinderen, jeugdigen als volwassenen met ASS is nodig om zicht te krijgen op het beloop, de stabiliteit en verandering van deze dimensies door de tijd heen. Onderzoek naar persoonlijkheid(spathologie) en ASS is, ook in de studies in dit proefschrift, voornamelijk correlatief van aard: toekomstig onderzoek zou zich moeten richten op de oorzakelijke verbanden tussen ASS en persoonlijkheid(spathologie). Tot slot verdient het in toekomstig onderzoek de aandacht welke behandeling voor persoonlijkheidspathologie uiteindelijk het meest effectief zal zijn voor volwassenen met ASS en comorbide persoonlijkheidsstoornis.

References

References marked with an asterisk indicate studies included in the systematic review (Chapter 3). References marked with a plus sign indicate studies included in the systematic review and meta-analysis (Chapter 3).

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Addendum



Appendix 1 - NIDA (Original Dutch version)

Nederlands

Interview ten behoeve van

Diagnostiek

Autismespectrumstoornis bij volwassenen (NIDA)



R. Vuijk
Klinisch psycholoog

Tweede druk 2016

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Inleiding

Het Nederlands Interview ten behoeve van Diagnostiek Autismespectrumstoornis bij volwassenen (NIDA) is gebaseerd op de DSM-5-classificatiecriteria voor de autismespectrumstoornis (ASS) (American Psychiatric Association, 2014; 2013). De NIDA is een Nederlandstalig interview ten behoeve van de classificatie en diagnostiek van de ASS bij volwassenen. De NIDA is ontwikkeld door Richard Vuijk, klinisch psycholoog.

Voor de classificatie ASS bij volwassenen gaat het volgens de DSM-5 om persisterende deficiënties in de sociale communicatie en sociale interactie en beperkte, repetitieve gedragspatronen, interesses of activiteiten. De kenmerken moeten aanwezig zijn in de vroege ontwikkelingsperiode, maar worden wellicht pas volledig manifest wanneer de sociale eisen vanuit de omgeving de begrensde vermogens van de persoon overstijgen of kunnen gemaskeerd worden door ondersteuning of op latere leeftijd aangeleerde strategieën. Voor de vroege ontwikkelingsperiode wordt in de DSM-5 geen leeftijd aangegeven, maar in ieder geval zijn de kenmerken van de ASS het meest uitgesproken in de vroege kindertijd en tijdens de eerste schooljaren. Onder de vroege ontwikkelingsperiode wordt dan ook in de NIDA de (vroege) kindertijd verstaan. Met de NIDA kan men de aanwezigheid of afwezigheid van de DSM-5-classificatiecriteria voor de ASS in het actuele functioneren (d.w.z. in de volwassenheid) en in de vroege ontwikkelingsperiode (lees: kindertijd) beoordelen. De vragen zijn voorzien van (concrete) voorbeelden voor beide levensfasen om het beoordelen te vergemakkelijken. De voorbeelden zijn gebaseerd op de DSM-5 en literatuur over de ASS.

De NIDA kan worden afgenomen bij de volwassen cliënt (b.v. als onderdeel van een psychodiagnostiektraject), bij partner, familielid en begeleider, mentor of coach (b.v. als onderdeel van een heteroanamnese). De afname van de NIDA varieert in duur van ongeveer 45 tot 90 minuten.

Met de NIDA wordt uitsluitend gevraagd naar de DSM-5-classificatiecriteria voor de ASS. Meer dan 70% van de mensen met een ASS is bekend met een bijkomende somatische of genetische aandoening, andere neurobiologische ontwikkelingsstoornissen, psychische stoornissen en/of omgevingsproblemen (Lai, Lombardo & Baron-Cohen, 2014; Mannion & Leader, 2013; Tebartz van Elst et al., 2013). Daarom is alleen het inventariseren van gedrag ofwel het 'afvinken' van de DSM-5-classificatiecriteria (met de NIDA) niet voldoende om een ASS vast te stellen (Vermeulen, 2013). Men dient tevens na te gaan of bepaalde problemen door een comorbide stoornis verklaard kunnen worden. Het is eveneens belangrijk om na te gaan of de gedragskenmerken niet door iets anders dan een ASS en eventuele comorbide stoornis verklaard kunnen worden. Voor zowel onderzoek naar een ASS, comorbiditeit als naar een differentiële diagnose is meer nodig dan alleen een afname van de NIDA. Men dient de met de NIDA verkregen informatie dan ook te (over)wegen in een psychodiagnostisch onderzoek naar een ASS, welke volgens de *Multidisciplinaire richtlijn diagnostiek en behandeling van autismespectrumstoornissen bij volwassenen* (Kan et al., 2013; zie ook Kan, 2012) ten minste bestaat uit een brede klinische psychodiagnostiek (d.w.z. het signaleren van psychopathologie), een ontwikkelingsanamnese en een heteroanamnese. Daarnaast dient de verkregen informatie gewogen te worden in de context van het actuele persoonlijke functioneren van de cliënt, de voorgeschiedenis, de hechting, de opvoeding, somatische factoren en de sterke en gezonde kanten. Op deze manier ontstaan een uitgebreide onderkenning van en een goed gemotiveerd verklaringsmodel voor de klachten, dat de (ASS-)diagnose wordt genoemd (Kan et al., 2013; Klin, Saulnier, Tsatsanis & Volkmar, 2005; Witteman, Van der Heijden & Claes, 2014; zie ook Ruissen, 2014). Hierbij is het van belang dat overwogen wordt of het te verwachten positieve effect van een DSM-5-classificatie ASS opweegt tegen het eventuele negatieve effect ervan (Duker, 2013).

De NIDA voorziet de psychodiagnosticus van een formulier voor scoring en psychodiagnostische overweging met zowel de DSM-5-classificatiecriteria voor de ASS als vragen of de met de NIDA verkregen informatie gewogen is in de context van verschillende onderzoeksmethoden en differentieële diagnoses. U geeft als psychodiagnosticus uw redeneren en beoordelen op transparante wijze weer en onderbouwt uw beslissingen (Eurelings-Bontekoe & Snellen, 2013), waarbij in een interactief proces de relatie met de cliënt en intersubjectiviteit de uitslag van de (over)weging meebepalen (Beekman & Hengeveld, 2014).

In de *Multidisciplinaire richtlijn diagnostiek en behandeling van autismespectrumstoornissen bij volwassenen* (Kan et al., 2013) wordt op grond van literatuuronderzoek gesteld dat er geen enkel instrument is dat op grond van psychometrische data aangemerkt kan worden als een gouden standaard voor de classificatie en diagnose ASS bij volwassenen. Voor meer informatie over vragenlijsten en tests in de psychodiagnostiek van een ASS bij volwassenen wordt verwezen naar Kan, Verbeeck en Bartels (2012) en Vuijk (2012). Vooral nog kan een ASS alleen op gedragsniveau worden geclassificeerd en gediagnosticeerd op basis van de beschrijving, observatie en klinische evaluatie van het gedrag van het individu (Blijd-Hoogewys, 2013).

De NIDA kan worden afgenomen door een psycholoog, gezondheidszorgpsycholoog, klinisch (neuro)psycholoog, psychotherapeut, psychiater en verpleegkundig specialist. Men dient bekwaam te zijn in de psychodiagnostiek en te beschikken over kennis van en ervaring met de ASS bij volwassenen. De uiteindelijke classificatie en diagnose ASS mag volgens de *Multidisciplinaire richtlijn diagnostiek en behandeling van autismespectrumstoornissen bij volwassenen* (Kan et al., 2013) alleen door een (bevoegd en bekwaam) gezondheidszorgpsycholoog, klinisch (neuro)psycholoog, psychiater en verpleegkundig specialist worden vastgesteld.

Instructies voor het afnemen van de NIDA

De NIDA bestaat uit acht vragen die afgeleid zijn van de DSM-5-classificatiecriteria voor de autismespectrumstoornis (ASS). Bij elke vraag staan voorbeelden genoteerd die gebaseerd zijn op de DSM-5 en literatuur over de ASS.

U leest als psychodiagnosticus elke vraag met een voorbeeld voor en vraagt aan degene die u interviewt of deze het kenmerk in het actuele functioneren (de volwassenheid) en/of in de vroege ontwikkelingsperiode (kindertijd) herkent. Bij herkenning vraagt u vervolgens of de geïnterviewde één of enkele voorbeelden daarvan kan geven. Wanneer men een voorbeeld geeft dat bij de vraag genoteerd staat, kan dat als aanwezig worden aangekruist. U legt vervolgens nog één of enkele voorbeelden voor (b.v. ook als vraagstelling) en dit doet u zeker als men het kenmerk niet herkent of als het gegeven antwoord niet past bij de vraag. U kruist vervolgens elk voorbeeld aan dat de geïnterviewde geeft of herkent. Bij 'overig' kunt u andere voorbeelden noteren die men geeft en die passend zijn bij de vraag. Om de vraag met 'ja' te beantwoorden hoeft men niet te voldoen aan alle voorbeelden. U dient per vraag een duidelijk beeld te krijgen van de aanwezigheid of afwezigheid van het kenmerk voor zowel het actuele functioneren (de volwassenheid) als de vroege ontwikkelingsperiode (kindertijd). Met behulp van vraag 8 kunt u duidelijkheid krijgen of de kenmerken klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of het functioneren op andere belangrijke terreinen veroorzaken. Sommige vragen bestaan uit één of meer deelvragen: wanneer blijkt dat men de vraag niet begrijpt of te lang vindt, dan kunt u de vraag nog eens herhalen en verduidelijken met het geven van een voorbeeld of dan stelt u één voor één de deelvragen.

U kunt de vragen voor het actuele functioneren (de volwassenheid) en de vroege ontwikkelingsperiode (kindertijd) stellen aan cliënten met een

ten minste gemiddelde intelligentie. U dient er rekening mee te houden, dat er mensen met een ASS zijn die niet in staat zijn om te reflecteren op zichzelf en te vertellen wat ze denken, voelen en ervaren (Jackson, Skirrow & Hare, 2012). Zo geven Kan et al. (2013) aan, dat de persoon met een ASS soms geen lijdensdruk ervaart en geen ziekteinzicht heeft, terwijl de omgeving wel duidelijke problemen signaleert. U kunt dan overwegen om de NIDA niet bij de cliënt af te nemen, maar alleen bij overige betrokkenen als partner, familielid of begeleider, mentor of coach. Er zijn ook mensen met een ASS en een ten minste gemiddelde intelligentie, die zelfinzicht hebben in tegenstelling tot de wijdverspreide en hardnekkige veronderstelling, dat zij zelfinzicht missen en niet in staat zijn tot zelfreflectie (Schriber, Robins & Solomon, 2014). Gebleken is, dat zij in staat zijn om vragen over hun klachten en beperkingen en hun functioneren door de jaren heen te beantwoorden. Bij hen kunt u de NIDA afnemen.

U kunt de vragen voor het actuele functioneren (de volwassenheid) en de vroege ontwikkelingsperiode (kindertijd) stellen aan partner, familielid of begeleider, mentor of coach. Een familielid (b.v. vader of moeder) kent de cliënt vanaf de vroege ontwikkelingsperiode (kindertijd) en kan vaak vragen over die periode en over de periode vóór het actuele functioneren (d.w.z. vóór de volwassenheid) beantwoorden. Aan een partner, familielid of een begeleider, mentor of coach kunt u vragen over het actuele functioneren (de volwassenheid) stellen. De informatie die door partner, familielid of begeleider, mentor of coach gegeven wordt, is aanvullend op die van de cliënt. Bij tegenstrijdige antwoorden legt u dit voor aan uw cliënt indien van toepassing en mogelijk. U geeft redelijkerwijs en rekening houdend met de mate van reflectie en zelfinzicht het beste de voorkeur aan de informatie van de cliënt.

Bij het afnemen van de NIDA kunt u als psychodiagnosticus kenmerken van de ASS bij de cliënt waarnemen, terwijl cliënt (en eventueel overige informanten) deze niet zelf herkennen en bij de

vragen aangeven. U kunt er dan voor kiezen om in en na overleg met uw cliënt (indien mogelijk) deze kenmerken bij de betreffende vragen aan te kruisen.

U kunt de NIDA afnemen bij de cliënt in de intakefase of in de fase van psychodiagnostisch onderzoek. Wanneer de cliënt vergezeld wordt door partner, familielid, begeleider, mentor of coach kunnen de vragen zowel aan de cliënt als aan de betrokken ander gesteld worden. De NIDA kan in afwezigheid van de cliënt afgenomen worden bij een partner of begeleider, mentor of coach in het kader van een heteroanamnese en bij een familielid in het kader van een ontwikkelingsanamnese of heteroanamnese waarvoor verschillende autismespecifieke meetinstrumenten als interviews en zelfinvulvragenlijsten bestaan (zie Van Oosten, Oosterhoff & Kan, 2012). De afname van de NIDA bij een partner, familielid, begeleider, mentor of coach in het kader van een heteroanamnese en ontwikkelingsanamnese kan dan gezien worden als aanvulling op deze meetinstrumenten.

Uitleg vooraf aan cliënt en overige betrokkenen over het afnemen van de NIDA

U geeft als psychodiagnosticus de volgende uitleg vooraf aan de cliënt:

Met behulp van dit interview worden de kenmerken van de autismespectrumstoornis (ASS) bij u onderzocht in het actuele functioneren in de volwassenheid (en indien mogelijk in de vroege kindertijd). De vragen zijn gebaseerd op de officiële classificatiecriteria voor de ASS in de DSM-5. Per criterium vraag ik u of u het kenmerk en een voorbeeld daarvan herkent. Ik vraag u ook of u zelf nog één of enkele voorbeelden kunt geven. Tijdens het interview zal ik u per vraag steeds één of enkele voorbeelden geven die beschrijven op welke manier volwassenen (en kinderen) last kunnen hebben van de kenmerken van de ASS. Uw actuele functioneren (en indien mogelijk uw functioneren in de vroege*

kindertijd*) breng ik met u in kaart om een ASS te kunnen overwegen. Wanneer u aangeeft dat u de vraag niet begrijpt of te lang vindt, dan zal ik de vraag uitleggen met een voorbeeld of herhalen, of dan stel ik de vraag in een kortere vorm aan u.

Indien van toepassing: Uw partner kent u waarschijnlijk vanaf de volwassenheid en ik zal vragen of hij/zij over die periode informatie over uw functioneren kan geven. Uw familie kent u vanaf de vroege kindertijd en ik zal vragen of zij over die periode (en indien mogelijk uw actuele functioneren) kunnen vertellen.

U geeft als psychodiagnosticus de volgende uitleg vooraf aan de partner:

Met behulp van dit interview worden de kenmerken van de autismespectrumstoornis (ASS) in het actuele functioneren van uw partner onderzocht. De vragen zijn gebaseerd op de officiële classificatiecriteria voor de ASS in de DSM-5. Per criterium vraag ik u of u het kenmerk en een voorbeeld daarvan herkent. Ik vraag u ook of u zelf nog één of enkele voorbeelden kunt geven. Tijdens het interview zal ik u per vraag steeds één of enkele voorbeelden geven die beschrijven op welke manier volwassenen last kunnen hebben van de kenmerken van de ASS. Wanneer u aangeeft dat u de vraag niet begrijpt of te lang vindt, dan zal ik de vraag uitleggen met een voorbeeld of herhalen, of dan stel ik de vraag in een kortere vorm aan u.

U geeft als psychodiagnosticus de volgende uitleg vooraf aan het familielid:

Met behulp van dit interview worden de kenmerken van de autismespectrumstoornis (ASS) in de vroege kindertijd* (en indien mogelijk in het actuele functioneren) van uw zoon/dochter/broer/zus** onderzocht. De vragen zijn gebaseerd op de officiële classificatiecriteria voor de ASS in de DSM-5. Per criterium vraag ik u of u het kenmerk en een voorbeeld daarvan herkent. Ik vraag u ook of u zelf nog één of enkele voorbeelden kunt geven. Tijdens het interview zal ik u per vraag steeds één of enkele voorbeelden geven die beschrijven op welke manier kinderen en jongeren (en indien van toepassing volwassenen) last kunnen hebben van de kenmerken van de ASS. Wanneer u aangeeft dat u

de vraag niet begrijpt of te lang vindt dan zal ik de vraag uitleggen met een voorbeeld of herhalen, of dan stel ik de vraag in een kortere vorm aan u.

U geeft als psychodiagnosticus de volgende uitleg vooraf aan de begeleider, mentor of coach***: Met behulp van dit interview worden de kenmerken van de autismespectrumstoornis (ASS) in het actuele functioneren van uw cliënt onderzocht. De vragen zijn gebaseerd op de officiële classificatiecriteria voor de ASS in de DSM-5. Per criterium vraag ik u of u het kenmerk en een voorbeeld daarvan herkent. Ik vraag u ook of u zelf nog één of enkele voorbeelden kunt geven. Tijdens het interview zal ik u per vraag steeds één of enkele voorbeelden geven die beschrijven op welke manier volwassenen last kunnen hebben van de kenmerken van de ASS. Wanneer u aangeeft dat u de vraag niet begrijpt of te lang vindt, dan zal ik de vraag uitleggen met een voorbeeld of herhalen, of dan stel ik de vraag in een kortere vorm aan u.

* Onder de vroege kindertijd worden de vroege ontwikkelingsperiode en de eerste schooljaren verstaan. Een ASS kan geclassificeerd worden na deze periode, wanneer bijvoorbeeld de sociale eisen vanuit de omgeving de begrensde vermogens van de persoon overstijgen en er problemen ontstaan of de kenmerken van de ASS gemaskeerd worden door ondersteuning, compenserend gedrag of interventies. Duidelijk moet dan wel zijn dat de ASS-kenmerken al in de vroege ontwikkelingsperiode (kindertijd) aanwezig zijn.

** De juiste verhouding tot het familielid aangeven.

*** Wanneer bij de cliënt sprake is van een verstandelijke beperking, kan de NIDA afgenomen worden bij een begeleider, mentor of coach.

Instructies voor het scoren van de NIDA

Voor het scoren van de NIDA maakt u gebruik van:

- Formulier voor samenvatting van de kenmerken van de autismespectrumstoornis (p. 22)
- Formulier voor scoring en psychodiagnostische overweging (p. 23)
- Formulier voor mate van actuele ernst van de autismespectrumstoornis (p. 26)

Instructies voor het scoren van de vragen 1 tot en met 8.

Per vraag heeft u tijdens of na afname van de NIDA per geïnterviewde aangegeven of het kenmerk aan- of afwezig is in zowel het actuele functioneren (d.w.z. in de volwassenheid) als in de vroege ontwikkelingsperiode (d.w.z. in de kindertijd). Nadat u de informatie van de cliënt en eventuele overige betrokkenen als partner, familielid of begeleider, mentor of coach beoordeeld heeft, scoort u de vragen 1 tot en met 7 samenvattend bevestigend (met 'Ja') voor het actuele functioneren (de volwassenheid) en de vroege ontwikkelingsperiode (kindertijd) als het kenmerk aanhoudend aanwezig is en het vaker voorkomt of ernstiger is dan bij een vergelijkbare groep mensen wat betreft leeftijd en intelligentie.

Wanneer in het actuele functioneren (de volwassenheid) en/of de vroege ontwikkelingsperiode (kindertijd) de kenmerken gemaskeerd worden door ondersteuning, compenserend gedrag of interventies, en bij doorvragen naar het hoe en waarom van het functioneren duidelijk (en zichtbaar) wordt dat het ogenschijnlijk goede sociale functioneren in werkelijkheid heel veel moeite en inspanning kost, scoort u de vragen 1 tot en met 7 samenvattend bevestigend (met 'Ja') voor het actuele functioneren (de volwassenheid) en/of de vroege ontwikkelingsperiode (kindertijd). Wanneer men als volwassene bijvoorbeeld geleerd heeft om repetitief gedrag te onderdrukken in het openbaar en specifieke belangstelling of hobby een bron van plezier en motiverende factor kan zijn en soms mogelijkheden opent tot het volgen van een opleiding en het verkrijgen van een baan kunnen de kenmerken van het DSM-5-ASS-criterium B (de vragen 4 tot en met 7) niet langer aanwezig zijn in het actuele functioneren (de volwassenheid). Dit hoeft toekenning van de DSM-5-classificatie ASS niet uit te sluiten als uit de rest van het onderzoek gegronde psychodiagnostische overwegingen zijn aan te nemen dat er sprake is van een ASS en als in ieder geval gedurende de vroege ontwikkelingsperiode (kindertijd) of in een bepaalde periode in het verleden duidelijk sprake was van beperkte, repetitieve gedragspatronen, interesses of activiteiten.

Wanneer informatie over de vroege ontwikkelingsperiode (kindertijd) ontbreekt, niet betrouwbaar of twijfelachtig is, noteert u samenvattend het vraagteken (?) bij de vragen 1 tot en met 8 voor de vroege ontwikkelingsperiode (kindertijd). Dit hoeft toekenning van de DSM-5-classificatie ASS niet uit te sluiten als uit de rest van het onderzoek gegronde psychodiagnostische overwegingen zijn aan te nemen dat er sprake is van een ASS. Er zijn dan ten minste geen aanwijzingen dat de sociale en communicatievaardigheden in de vroege ontwikkelingsperiode (kindertijd) goed waren.

Met behulp van de antwoorden op vraag 8 maakt u duidelijk of de kenmerken klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of het functioneren op andere belangrijke terreinen veroorzaken. Nadat u de informatie van de cliënt en eventuele overige betrokkenen als partner, familielid of begeleider, mentor of coach beoordeeld heeft, scoort u vraag 8 samenvattend bevestigend (met 'Ja') als de kenmerken klinisch significante lijdensdruk of beperkingen in het functioneren veroorzaken. Wanneer weinig tot geen last of beperking in het functioneren door ondersteuning, compenserend gedrag of interventies blijkt, overweegt u eveneens een samenvattende bevestigende score ('Ja'), wanneer het zo optimaal mogelijke functioneren alleen met zeer veel inspanning door betrokkene(n) haalbaar is.

Instructies voor het invullen van het formulier voor samenvatting van de kenmerken van de autismespectrumstoornis

Op het formulier voor samenvatting van de kenmerken van de autismespectrumstoornis (p. 22) geeft u aan welke van de zeven vragen (d.w.z. de zeven kenmerken van de DSM-5-ASS-criteria A en B) samenvattend bevestigend (met 'Ja') zijn gescoord in het actuele functioneren (de volwassenheid) en in de vroege ontwikkelingsperiode (kindertijd) en telt u de kenmerken per criterium afzonderlijk op.

Instructies voor het invullen van het formulier voor scoring en psychodiagnostische overweging

Uitleg bij de tien stappen op het formulier voor scoring en psychodiagnostische overweging (p. 23):

1. Noteer de naam en geboortedatum van de cliënt. Geef aan wanneer en door wie de NIDA is afgenomen. Geef aan bij wie de NIDA is afgenomen. De NIDA kan bij één of meerdere personen afgenomen zijn.
2. Geef voor DSM-5-ASS-criteria A en B aan of het aantal kenmerken van het DSM-5-ASS-criterium A drie (van drie) bedraagt en het aantal kenmerken van het DSM-5-ASS-criterium B twee of meer (van vier) bedraagt voor zowel het actuele functioneren (de volwassenheid) als de vroege ontwikkelingsperiode (kindertijd). Hiervoor neemt u de scores op het formulier voor samenvatting van de kenmerken van de autismespectrumstoornis (zie p. 22) over.
3. Geef voor DSM-5-ASS-criterium C aan of de kenmerken een levenslang beloop kennen, d.w.z. dat de kenmerken zowel aanwezig zijn in het actuele functioneren (de volwassenheid) als in de vroege ontwikkelingsperiode (kindertijd). Een ASS kan geclassificeerd worden na de vroege ontwikkelingsperiode (kindertijd) wanneer bijvoorbeeld de sociale eisen vanuit de omgeving de begrensde vermogens van de persoon overstijgen en er problemen ontstaan of de kenmerken van de ASS gemaskeerd worden door ondersteuning, compenserend gedrag of interventies. Duidelijk moet zijn dat de ASS-kenmerken al in de vroege ontwikkelingsperiode (kindertijd) aanwezig zijn.
4. Geef voor DSM-5-ASS-criterium D aan of de kenmerken klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of in het functioneren op andere belangrijke terreinen veroorzaken. Hiervoor beoordeelt u de antwoorden op vraag 8.
5. Geef voor DSM-5-ASS-criterium E aan of de kenmerken niet verklaard kunnen worden door een verstandelijke beperking (verstandelijke-ontwikkelingsstoornis) of een globale ontwikkelingsachterstand.

6. Specificeer of:

- sprake is van een bijkomende verstandelijke beperking en vermeld deze
 - sprake is van een taalstoornis en vermeld deze
 - de kenmerken samengaan met een bekende somatische of genetische aan-doening of omgevingsfactor en vermeld deze
 - de kenmerken samengaan met een andere neurobiologische ontwikkelings-, psychische of gedragsstoornis en vermeld deze
 - de kenmerken samengaan met katatonie en gebruik de aanvullende code 293.89 katatonie bij autismespectrumstoornis om de aanwezigheid van de comorbide katatonie aan te geven.
7. Geef aan of de informatie verkregen met de NIDA is gewogen in de context van andere onderzoeksmethoden en vermeld deze.
 8. Geef aan of de kenmerken niet beter verklaard worden door de aanwezigheid van een andere stoornis en/of omgevingsproblemen. Vermeld vervolgens welke andere stoornissen en/of omgevingsproblemen u differentiaaldiagnostisch overweegt.
 9. Wanneer u bovenstaande stappen hebt doorlopen en alle vetgedrukte 'Ja' op het formulier voor scoring en psychodiagnostische overweging (p. 23) hebt omcirkeld, overweegt u of het te verwachten positieve effect van een DSM-5-classificatie ASS opweegt tegen het eventuele negatieve effect ervan. Daarna overweegt u als of in samenspraak met een gezondheidszorgpsycholoog, klinisch (neuro) psycholoog, psychiater of verpleegkundig specialist de classificatie ASS.
 10. Tot slot specificeert u de mate van ernst van de ASS voor het actuele functioneren (de volwassenheid). Om de ernst te bepalen maakt u gebruik van het formulier voor mate van actuele ernst van de autismespectrumstoornis. Zie daarvoor pagina 26.

Instructies voor het invullen van het formulier voor mate van actuele ernst van de autismespectrumstoornis

U kunt de mate van ernst van de ASS voor het actuele functioneren (de volwassenheid) specificeren (volgens DSM-5) op het formulier voor mate van actuele ernst van de autismespectrumstoornis (p. 26). Om de behoefte aan ondersteuning voor de domeinen 'sociale communicatie' en 'beperkt, repetitief gedrag' met 'Ja' te beantwoorden, dienen per domein alle bijbehorende gedragscriteria met 'Ja' beantwoord te worden bij één van de drie niveaus van ernst. De mogelijkheid bestaat dat de actuele ernst van de beperking voor een cliënt verschillende niveaus van ondersteuning vereist (b.v. niveau 1 voor de sociale communicatie en niveau 2 voor beperkt, repetitief gedrag).

Om het proces van psychodiagnostisch onderzoek naar een ASS inzichtelijk te maken voor de cliënt, eventuele verwijzer en/of toekomstige hulpverlener kunt u ervoor kiezen om het formulier voor samenvatting van de kenmerken van de autismespectrumstoornis, het formulier voor scoring en psychodiagnostische overweging en het formulier voor mate van actuele ernst van de autismespectrumstoornis in een bijlage van het psychodiagnostisch rapport van de cliënt op te nemen.

Referenties

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Arlington, VA: American Psychiatric Association.

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Nederlands Interview ten behoeve van Diagnostiek Autismespectrumstoornis bij volwassenen

Naam van de cliënt _____

Geboortedatum _____

Leeftijd _____ jaar

Geslacht man/vrouw

Datum onderzoek _____

Naam psychodiagnosticus _____

Functie psychodiagnosticus
 psycholoog
 gezondheidszorgpsycholoog
 klinisch psycholoog
 klinisch neuropsycholoog
 psychotherapeut
 psychiater
 verpleegkundig specialist

Afgenomen bij
 cliënt
 partner
 familielid
zo ja, vermeld: _____
 begeleider/mentor/coach

Aanvullende informatie

Opmerking 1

Bij het afnemen van de NIDA bij andere informanten dan de cliënt dient de formulering aangepast te worden, b.v.: 'Bent u...' wordt 'Is ...' etc.

Opmerking 2

In de voorbeelden bij de vragen 2 en 3 kan 'atypisch' gelezen worden als afwijkend van het gemiddelde.

Advies

Wanneer meer dan één informant betrokken wordt bij het interview, kunt u er voor kiezen om de antwoorden en de scores per informant in verschillende kleuren weer te geven bij de vragen en op de formulieren, b.v.: zwart voor de cliënt en blauw voor de partner.

Vraag 1
DSM-5-ASS-criterium A: kenmerk 1

Bent u beperkt in het leggen van contact met anderen en in het delen van gedachten en gevoelens, bijvoorbeeld steeds moeten inschatten wat voor de meeste mensen in contact vanzelfsprekend is? (Bent u beperkt in het leggen van contact met anderen? Bent u beperkt in het delen van gedachten en gevoelens? Bijvoorbeeld steeds moeten inschatten wat voor de meeste mensen in contact vanzelfsprekend is.)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?
En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Steeds moeten inschatten wat voor de meeste mensen in contact vanzelfsprekend is (wanneer en hoe men aan een gesprek gaat deelnemen; wat men wel/niet hoort te zeggen)
- Niet in staat om sociale interactie te beginnen, erop in te gaan of gaande te houden
- Verminderd tot niet in staat om over-en-weer-gesprekken aan te gaan (monoloog; door anderen heen praten)
- In de taal en in het spreken ontbreekt sociale wederkerigheid: verzoeken doen of etiketteren, maar geen gesprek voeren
- Alleen vanuit eigen standpunt en beleving reageren
- Niet afstemmen op en geen rekening houden met anderen en hun emoties
- Verminderd tot niet delen en begrijpen van emoties (blij, bang, boos, bedroefd)
- Verminderd tot niet delen van interesses
- Zwak in sociaal wederkerig gesprek en sterk in theoretisch-inhoudelijk gesprek
- Bij compenserende strategieën zijn er nog steeds sociale problemen in nieuwe situaties of in situaties waarin men geen ondersteuning krijgt
- Overig:

Voorbeelden kindertijd

- Niet of nauwelijks vertonen van initiatieven tot sociale interactie
- De ander op een ongewone manier benaderen (duidelijk afwijkend van wat gangbaar en leeftijdsadequaat is)
- Alleen reageren op een zeer directe sociale toenadering
- De ander benaderen om alleen aan de eigen behoefte te voldoen
- Verminderde of afwezige nabootsing van het gedrag van anderen
- Verminderd tot niet delen van interesses
- Verminderd tot niet in staat om over-en-weer-gesprekken aan te gaan (monoloog over bepaalde onderwerpen; door anderen heen praten)
- In de taal en in het spreken ontbreekt sociale wederkerigheid: verzoeken doen of etiketteren, maar geen gesprek voeren
- Verminderd tot niet delen en begrijpen van emoties (blij, bang, boos, bedroefd)
- Moeite met inschatten wanneer en hoe sociaal emotioneel reageren gepast is (lachen wanneer een ander kind verdriet toont; kan als erg eigenwijs, bot en tactloos overkomen)
- Komt in contact emotioneel jonger over dan leeftijdgenoten
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 2
DSM-5-ASS-criterium A: kenmerk 2

Bent u beperkt in uw communicatie zonder woorden, bijvoorbeeld gebruik van oogcontact? (Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?
En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Afwezig, verminderd en/of atypisch gebruik van oogcontact (niet aankijken, starend kijken, door de ander heen kijken)
- Afwezig, verminderd en/of atypisch gebruik van gebaren (niet omschrijven en uitbeelden met de handen in communicatie; moeite om spontaan expressieve gebaren te gebruiken in de communicatie)
- Afwezig, verminderd en/of atypisch gebruik van gezichtsuitdrukkingen
- Afwezig, verminderd en/of atypisch gebruik van lichaamstaal (vreemde, houterige of overdreven lichaamstaal)
- Verminderd tot niet 'lezen' van en reageren op oogcontact, gebaren, gezichtsuitdrukkingen en/of lichaamstaal van anderen
- Gezichtsuitdrukkingen beredenerend i.p.v. intuïtief begrijpen
- Afwijkende intonatie in spreken, niet passend bij de inhoud van het gesprek (langzaam, snel, hard, zacht, nadrukkelijk, onduidelijk, niet afgestemd)
- Relatief subtiele beperkingen, maar zichtbaar in slechte integratie van oogcontact, gebaren, gezichtsuitdrukkingen, lichaamshouding en ritme, klemtoon en intonatie van de stem ten behoeve van de sociale communicatie
- Overig:

Voorbeelden kindertijd

- Afwezig, verminderd en/of atypisch gebruik van oogcontact (niet aankijken, starend kijken, door de ander heen kijken)
- Afwezig, verminderd en/of atypisch gebruik van gebaren (niet omschrijven en uitbeelden met de handen in communicatie; moeite om spontaan expressieve gebaren te gebruiken in de communicatie)
- Afwezig, verminderd en/of atypisch gebruik van gezichtsuitdrukkingen (bij twaalf maanden niet wederkerig lachen naar de ander)
- Afwezig, verminderd en/of atypisch gebruik van lichaamstaal (vreemde, houterige of overdreven lichaamstaal)
- Verminderd vermogen tot gezamenlijke aandacht (geen voorwerpen aanwijzen, laten zien of meenemen om interesses met anderen te delen; niet in staat om de wijzende vinger of gerichte blik van een ander te volgen)
- Verminderd tot niet 'lezen' van en reageren op oogcontact, gebaren, gezichtsuitdrukkingen en/of lichaamstaal van anderen
- Afwijkende intonatie in spreken, niet passend bij de inhoud van het gesprek (langzaam, snel, hard, zacht, nadrukkelijk, onduidelijk, niet afgestemd)
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 3
DSM-5-ASS-criterium A: kenmerk 3

Bent u beperkt in het beginnen, gaande houden en begrijpen van relaties, bijvoorbeeld star vasthouden aan sociale omgangsvormen?

(Bent u beperkt in het beginnen van relaties? Bent u beperkt in het gaande houden van relaties? Bent u beperkt in het begrijpen van relaties? Bijvoorbeeld star vasthouden aan sociale omgangsvormen.)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Sociaal gedrag komt aangeleerd over op anderen (star vasthouden aan sociale omgangsvormen; formeel)
- Afwezige, verminderde en/of atypische sociale belangstelling (afwijzen van anderen, passiviteit of een ongepaste bejegening die agressief kan lijken of storend kan zijn)
- De relatie met anderen verdiept zich niet, blijft oppervlakkig (geen contactgroei, niet reageren op contactaanbod)
- Moeite met het maken en onderhouden van vriendschappen (geen realistisch besef van wat vriendschap inhoudt; eenzijdige vriendschap; vriendschap louter gebaseerd op een gezamenlijke interesse)
- Geen belangstelling voor leeftijdsgenoten
- Geen belangstelling voor sociale relaties (instrumenteel/zakelijk contact)
- Voorkeur om alleen te zijn, alleen te leven (contact als onnodig, onprettig, belastend, vermoeiend ervaren; Einzelgänger)
- Beperkt tot niet begrijpen wat gepast gedrag is in verschillende situaties/relaties (thuis versus werk; nonchalant gedrag tijdens sollicitatie)
- Verminderd tot geen begrip van uiteenlopende manieren waarop taal gebruikt kan worden (ironie, leugentjes om bestwil, humor, fantasie, doen alsof, letterlijk nemen van taal)
- Overig:

Voorbeelden kindertijd

- Sociaal gedrag komt aangeleerd over op anderen (star vasthouden aan sociale omgangsvormen; formeel)
- Afwezige, verminderde en/of atypische sociale belangstelling (afwijzen van anderen, passiviteit of een ongepaste bejegening die agressief kan lijken of storend kan zijn)
- Afwezig, verminderd en/of atypisch sociaal spel en fantasiespel (aandringen om alleen spelletjes te spelen waarvan de regels duidelijk vastliggen; geen rol kunnen spelen)
- De relatie met anderen verdiept zich niet, blijft oppervlakkig (geen contactgroei; lijkt 'doof'; bij twaalf maanden niet 'sociaal interactief' brabbelen, niet reageren op contactaanbod)
- Moeite met het maken en onderhouden van vriendschappen (eenzijdige vriendschap; vriendschap louter gebaseerd op een gezamenlijke interesse)
- Geen belangstelling voor leeftijdsgenoten
- Geen belangstelling voor sociale relaties (instrumenteel contact)
- Voorkeur om alleen te zijn, alleen te leven (contact als onnodig, onprettig, belastend, vermoeiend ervaren; in de eigen wereld leven)
- Verminderd tot geen begrip van uiteenlopende manieren waarop taal gebruikt kan worden (humor, fantasie, doen alsof, letterlijk nemen van taal)
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 4
DSM-5-ASS-criterium B: kenmerk 1

Heeft u een vaste of herhalende manier van bewegen, van voorwerpen gebruiken of van spreken, bijvoorbeeld op en neer bewegen met lichaam, voorwerpen op volgorde zetten of letterlijk andermans woorden herhalen?

(Heeft u een vaste of herhalende manier van bewegen, bijvoorbeeld op en neer bewegen met lichaam? Heeft u een vaste of herhalende manier van voorwerpen gebruiken, bijvoorbeeld voorwerpen op volgorde zetten? Heeft u een vaste of herhalende manier van spreken, bijvoorbeeld letterlijk andermans woorden herhalen?)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Op een vaste of herhalende manier bewegen (op en neer bewegen met lichaam, fladderen met de armen en handen, klikken met de vingers)
- Op een vaste of herhalende manier voorwerpen gebruiken (niet functioneel; voorwerpen ronddraaien; voorwerpen op volgorde zetten)
- Op een vaste of herhalende manier spreken (bedenken van nieuwe woorden of uitdrukkingen; letterlijk ofwel zo exact mogelijk herhalen van andermans klanken, woorden of zinnen, onmiddellijk of uitgesteld; formeel en ouwelijk taalgebruik; gebruik van 'jij' als men naar zichzelf verwijst)
- Overig:

Voorbeelden kindertijd

- Op een vaste of herhalende manier bewegen (op en neer bewegen met lichaam, fladderen met de armen en handen, om de eigen as draaien)
- Op een vaste of herhalende manier voorwerpen gebruiken (speelgoed in een rij opstellen; voorwerpen ronddraaien)
- Op een vaste of herhalende manier spreken (bedenken van nieuwe woorden of uitdrukkingen; letterlijk ofwel zo exact mogelijk herhalen van andermans klanken, woorden of zinnen, onmiddellijk of uitgesteld; formeel en ouwelijk taalgebruik; gebruik van 'jij' als men naar zichzelf verwijst)
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 5
DSM-5-ASS-criterium B: kenmerk 2

Houdt u hardnekkig vast aan hetzelfde, heeft u starre (niet flexibele) routines of rituele patronen in uw manier van spreken of handelen, bijvoorbeeld moeite met veranderingen?

(Houdt u hardnekkig vast aan hetzelfde? Heeft u starre (niet flexibele) routines? Heeft u rituele patronen in uw manier van spreken? Heeft u rituele patronen in uw manier van handelen? Bijvoorbeeld moeite met veranderingen.)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Verzet tegen veranderingen (extreme spanning/overstuur bij veranderingen o.a. in tijd, volgorde, omgeving, afspraken; veranderingen met grote moeite ondergaan)
- Moeite met overgangssituaties (o.a. verhuizen, van baan veranderen, zomertijd/wintertijd, wisseling van seizoenen, feestdagen)
- Starre denkpatronen (regel is regel; wet is wet; tijd is tijd; afspraak is afspraak)
- Starre routines of rituele patronen (activiteiten in een bepaalde volgorde en op een vaste tijd moeten uitvoeren; behoefte om steeds dezelfde route te volgen; heen en weer lopen; elke dag hetzelfde eten; overdreven formeel of uitgebreid begroeten; herhalend vragen stellen)
- Overig:

Voorbeelden kindertijd

- Verzet tegen veranderingen (extreme spanning/overstuur bij veranderingen o.a. in tijd, volgorde, omgeving, afspraken; veranderingen met grote moeite ondergaan)
- Moeite met overgangssituaties (o.a. verhuizen, overgaan naar de volgende klas, zomertijd/wintertijd, wisseling van seizoenen, feestdagen)
- Starre denkpatronen (regel is regel; tijd is tijd; afspraak is afspraak)
- Starre routines of rituele patronen (activiteiten in een bepaalde volgorde en op een vaste tijd moeten uitvoeren; behoefte om steeds dezelfde route te volgen; heen en weer lopen; elke dag hetzelfde eten; overdreven formeel of uitgebreid begroeten; herhalend vragen stellen)
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 6
DSM-5-ASS-criterium B: kenmerk 3

Heeft u zeer beperkte, gefixeerde interesses die buitengewoon intens of gefocust zijn, bijvoorbeeld intensief verzamelen van informatie over een onderwerp?

(Heeft u zeer beperkte, gefixeerde interesses die buitengewoon intens zijn? Heeft u zeer beperkte, gefixeerde interesses die buitengewoon gefocust zijn? Bijvoorbeeld intensief verzamelen van informatie over een onderwerp.)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Zeer sterke voorkeur om bezig te zijn met (on)gewone voorwerpen of informatie (verzamelen, ordenen, bestuderen, fantaseren)
- Zeer beperkte interesses (voor slechts één onderwerp, activiteit)
- Verregaande, vasthoudende interesses (qua tijdsbesteding, niet op tijd kunnen stoppen)
- Inhoudelijk bijzondere interesses die op anderen vreemd overkomen
- Bezig zijn met de interesses belemmert de sociale interactie en het dagelijks functioneren
- Bezig zijn met de interesses neemt toe in tijden van stress en spanning
- Bezig zijn met de interesses neemt spanning weg (werkt ontspannend)
- Bezig zijn met de interesses komt dwangmatig over
- Verstoren van de interesses door de ander leidt tot verwarring, irritatie, boosheid, angst of spanning
- Overig:

Voorbeelden kindertijd

- Zeer sterke voorkeur om bezig te zijn met (on)gewone voorwerpen of informatie (verzamelen, ordenen, fantaseren)
- Zeer beperkte interesses (voor slechts één onderwerp, activiteit)
- Verregaande, vasthoudende interesses (qua tijdsbesteding, niet op tijd kunnen stoppen)
- Inhoudelijk bijzondere interesses die op anderen vreemd overkomen
- Bezig zijn met de interesses belemmert de sociale interactie en het dagelijks functioneren
- Bezig zijn met de interesses neemt toe in tijden van stress en spanning
- Bezig zijn met de interesses neemt spanning weg (werkt ontspannend)
- Bezig zijn met de interesses komt dwangmatig over
- Verstoren van de interesses door de ander leidt tot verwarring, irritatie, boosheid, angst of spanning
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familie lid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 7
DSM-5-ASS-criterium B: kenmerk 4

Reageert u over- of on(der)gevoelig op prikkels of heeft u er een ongewone belangstelling voor, bijvoorbeeld geluid, licht of geur?

(Reageert u over- of on[der]gevoelig op prikkels? Heeft u ongewone belangstelling voor prikkels?)

Bijvoorbeeld geluid, licht of geur.)

(Wanneer men 'ja' antwoordt:) Kunt u daarvan een voorbeeld geven?

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Onverschillig voor en/of niet aanvoelen en herkennen van pijn, temperatuur, geluid, licht, geur
- Overgevoelig voor en/of extreme reactie op pijn, temperatuur, geluid, licht, geur, voeding, kledingstoffen
- Visuele fascinatie/detailwaarneming (licht, bewegingen)
- Auditieve fascinatie/detailwaarneming (geluid, muziektönen)
- Aanraking door de ander niet verdragen of met grote moeite ondergaan
- Overmatig ruiken aan of aanraken van voorwerpen of personen
- Overig:

Voorbeelden kindertijd

- Onverschillig voor en/of niet aanvoelen en herkennen van pijn, temperatuur, geluid, licht, geur
- Overgevoelig voor en/of extreme reactie op pijn, temperatuur, geluid, licht, geur, voeding, kledingstoffen
- Visuele fascinatie/detailwaarneming (licht, bewegingen)
- Auditieve fascinatie/detailwaarneming (geluid, muziektönen)
- Aanraking door de ander niet verdragen of met grote moeite ondergaan
- Overmatig ruiken aan of aanraken van voorwerpen of personen
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

Vraag 8
DSM-5-ASS-criterium D

Op welke gebieden heeft u last van of bent u beperkt in uw functioneren door de eerder genoemde kenmerken, bijvoorbeeld tijdens uw werk?

(Op welke gebieden heeft u last van de eerder genoemde kenmerken? Op welke gebieden bent u beperkt in uw functioneren door de eerder genoemde kenmerken? Bijvoorbeeld tijdens uw werk.)

En hoe was dat in uw kindertijd?

Voorbeelden actuele functioneren

- Relatie/gezin
- Familie
- Sociale contacten, vrienden, kennissen
- Werk/dagbesteding/opleiding
- Vrije tijd, hobby, sport
- Zelfvertrouwen/zelfbeeld
- Weinig tot geen last of beperking in het functioneren door ondersteuning, compenserend gedrag of aangeleerde interventies (hetgeen gepaard gaat met zeer veel inspanning van betrokkene(n) om zo optimaal mogelijk te functioneren)
- Overig:

Voorbeelden kindertijd

- Gezin
- Familie
- Sociale contacten, vrienden, kennissen
- Peuterspeelzaal/kleuterschool/basisschool
- Vrije tijd, hobby, sport, spel
- Zelfvertrouwen/zelfbeeld
- Weinig tot geen last of beperking in het functioneren door ondersteuning, compenserend gedrag of aangeleerde interventies (hetgeen gepaard gaat met zeer veel inspanning van betrokkene(n) om zo optimaal mogelijk te functioneren)
- Overig:

Kenmerk aanwezig in actuele functioneren:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Kenmerk aanwezig in kindertijd:

Cliënt	Ja	?	Nee	Niet bij afgenomen
Partner	Ja	?	Nee	Niet bij afgenomen
Familielid	Ja	?	Nee	Niet bij afgenomen
Begeleider	Ja	?	Nee	Niet bij afgenomen

Samenvattend

Kenmerk aanwezig in actuele functioneren:	Ja	?	Nee
Kenmerk aanwezig in vroege ontwikkelingsperiode (kindertijd):	Ja	?	Nee

DSM-5-classificatiecriteria voor de autismespectrumstoornis

Autismespectrumstoornis

Autism spectrum disorder

299.00 CLASSIFICATIECRITERIA

A Persisterende deficiënties in de sociale communicatie en sociale interactie in uiteenlopende situaties, zoals blijkt uit de volgende actuele of biografische kenmerken (de voorbeelden zijn bedoeld als illustratie en geven geen volledig beeld):

- 1 Deficiënties in de sociaal-emotionele wederkerigheid, variërend van bijvoorbeeld op een abnormale manier sociaal contact maken en niet in staat zijn tot een normale gespreksinteractie; het verminderd delen van interesses, emoties of affect; een onvermogen om sociale interacties te initiëren en te beantwoorden; tot het niet in staat zijn om een sociale interactie te beginnen of erop in te gaan.
- 2 Deficiënties in het non-verbale communicatieve gedrag dat gebruikt wordt voor sociale interactie, variërend van bijvoorbeeld slecht geïntegreerde verbale en non-verbale communicatie; abnormaal gedrag bij oogcontact en lichaamstaal of deficiënties in het begrijpen en gebruiken van gebaren; tot een totaal ontbreken van gezichtsuitdrukkingen en non-verbale communicatie.
- 3 Deficiënties in het ontwikkelen, onderhouden en begrijpen van relaties, variërend van bijvoorbeeld problemen met het aanpassen van gedrag aan verschillende sociale omstandigheden; moeite met deelnemen aan fantasiespel of vrienden maken; tot afwezigheid van belangstelling voor leeftijdgenoten.

→ *Specificeer* actuele ernst:
De ernst is gebaseerd op beperkingen in de sociale communicatie en beperkte, repetitieve gedragspatronen.

B Beperkte, repetitieve gedragspatronen, interesses of activiteiten, zoals blijkt uit minstens twee van de volgende actuele of biografische kenmerken (de voorbeelden zijn bedoeld als illustratie en geven geen volledig beeld):

- 1 Stereotiep(e) of repetitieve motorische bewegingen, gebruik van voorwerpen of spraak (zoals eenvoudige motorische stereotypieën, speelgoed in een rij zetten of voorwerpen ronddraaien; echolalie; idiosyncratische uitdrukkingen).
- 2 Hardnekkig vasthouden aan hetzelfde, inflexibel gehecht zijn aan routines of geritualiseerde patronen van verbaal of non-verbaal gedrag (bijvoorbeeld extreem overstuur bij kleine veranderingen, moeite met overgangen, rigide denkpatronen, rituele wijze van begroeten, de behoefte om steeds dezelfde route te volgen of elke dag hetzelfde te eten).
- 3 Zeer beperkte, gefixeerde interesses die abnormaal intens of gefocust zijn (bijvoorbeeld een sterke gehechtheid aan of preoccupatie met ongebruikelijke voorwerpen, bijzonder specifieke of hardnekkige interesses).
- 4 Hyper- of hyporeactiviteit op zintuiglijke prikkels of ongewone belangstelling voor de zintuiglijke aspecten van de omgeving (bijvoorbeeld duidelijk overgevoelig voor pijn en/of temperatuur, een negatieve reactie op specifieke geluiden of texturen, excessief ruiken aan of aanraken van voorwerpen, visuele fascinatie met lichten of beweging).

→ *Specificeer* actuele ernst:
De ernst is gebaseerd op beperkingen in de sociale communicatie en beperkte, repetitieve gedragspatronen.

C De symptomen moeten aanwezig zijn in de vroege ontwikkelingsperiode (maar kunnen soms pas volledig manifest worden wanneer de sociale eisen de begrensde vermogens overstijgen, of kunnen worden gemaskeerd door op latere leeftijd aangeleerde strategieën)

D De symptomen veroorzaken klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of het functioneren op andere belangrijke terreinen.

E De stoornissen kunnen niet beter worden verklaard door een verstandelijke beperking (verstandelijke-ontwikkelingsstoornis) of een globale ontwikkelingsachterstand. Een verstandelijke beperking en de autismespectrumstoornis komen geregeld samen voor; om de comorbide classificatie autismespectrumstoornis naast een verstandelijke beperking toe te kennen moet de sociale communicatie onder het verwachte algemene ontwikkelingsniveau liggen.

→ *Specificeer* indien:
Met of zonder bijkomende verstandelijke beperking
Met of zonder bijkomende taalstoornis
Samenhangend met een bekende somatische of genetische aandoening of omgevingsfactor (Vermeld de ermee samenhangende somatische of genetische aandoening.)
Samenhangend met een andere neurobiologische ontwikkelings-, psychische of gedragsstoornis (Vermeld de ermee samenhangende neurobiologische ontwikkelings-, psychische of gedragsstoornis(sen)).
Met katatonie (voor de definitie: zie de criteria voor katatonie bij een andere psychische stoornis, p. 199 in het Handboek voor de classificatie van psychische stoornissen. DSM-5.) (**Coderingsaanwijzing** Gebruik de aanvullende code 293.89 katatonie bij autismespectrumstoornis om de aanwezigheid van de comorbide katatonie aan te geven.)

Formulier voor samenvatting van de kenmerken van de autismespectrumstoornis

Vraag	Kenmerk	Aanwezig in actuele functioneren	Aanwezig in vroeg ontwikkelingsperiode
1	Deficiënties in de sociaal-emotionele wederkerigheid		
2	Deficiënties in het non-verbale communicatieve gedrag dat gebruikt wordt voor sociale interactie		
3	Deficiënties in het ontwikkelen, onderhouden en begrijpen van relaties		
Totaal aantal kenmerken van DSM-5-ASS-criterium A (Persisterende deficiënties in de sociale communicatie en sociale interactie)		<input type="checkbox"/> /3	<input type="checkbox"/> /3
4	Stereotiep(e) of repetitieve motorische bewegingen, gebruik van voorwerpen of spraak		
5	Hardnekkig vasthouden aan hetzelfde, inflexibel gehecht zijn aan routines of geritualiseerde patronen van verbaal of non-verbaal gedrag		
6	Zeer beperkte, gefixeerde interesses die abnormaal intens of gefocust zijn		
7	Hyper- of hyporeactiviteit op zintuiglijke prikkels of ongewone belangstelling voor de zintuiglijke aspecten van de omgeving		
Totaal aantal kenmerken van DSM-5-ASS-criterium B (Beperkte, repetitieve gedragspatronen, interesses of activiteiten)		<input type="checkbox"/> /4	<input type="checkbox"/> /4

Formulier voor scoring en psychodiagnostische overweging

1.

Naam van de cliënt _____

Geboortedatum _____ - ____ - ____

Datum onderzoek _____ - ____ - ____

NIDA afgenomen door

Naam psychodiagnosticus _____

Functie psychodiagnosticus _____

NIDA afgenomen bij

cliënt

partner

familielid

zo ja, vermeld deze: _____

begeleider/mentor/coach

2.

DSM-5-criterium A

Persisterende deficiënties in de sociale communicatie en sociale interactie in uiteenlopende situaties

Actuele functioneren:

Is het aantal kenmerken drie? Ja ? Nee

Vroege ontwikkelingsperiode:

Is het aantal kenmerken drie? Ja ? Nee

Ja

Nee

DSM-5-criterium B

Beperkte, repetitieve gedragspatronen, interesses of activiteiten

Actuele functioneren:

Is het aantal kenmerken minstens twee? Ja ? Nee

Vroege ontwikkelingsperiode:

Is het aantal kenmerken minstens twee? Ja ? Nee

Ja

Nee

3.

DSM-5-criterium C

De symptomen moeten aanwezig zijn in de vroege ontwikkelingsperiode (maar kunnen soms pas volledig manifest worden wanneer de sociale eisen de begrenste vermogens overstijgen, of kunnen worden gemaskeerd door op latere leeftijd aangeleerde strategieën).

Ja

Nee

4.

DSM-5-criterium D

De symptomen veroorzaken klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of het functioneren op andere belangrijke terreinen.

Ja

Nee

<p>5. DSM-5-criterium E De stoornissen kunnen niet beter worden verklaard door een verstandelijke beperking (verstandelijke-ontwikkelingsstoornis) of een globale ontwikkelingsachterstand. Een verstandelijke beperking en de autismespectrumstoornis komen geregeld samen voor; om de comorbide classificatie autismespectrumstoornis naast een verstandelijke beperking toe te kennen moet de sociale communicatie onder het verwachte algemene ontwikkelingsniveau liggen.</p>	Ja	Nee
<p>6. Specificeer indien: Met of zonder bijkomende verstandelijke beperking Zo ja, specificeer actuele ernst: <input type="checkbox"/> Licht <input type="checkbox"/> Matig <input type="checkbox"/> Ernstig <input type="checkbox"/> Diep</p>	Ja	Nee
<p>Met of zonder bijkomende taalstoornis Zo ja, vermeld deze: _____</p>	Ja	Nee
<p>Samenhangend met een bekende somatische of genetische aandoening of omgevingsfactor Zo ja, vermeld deze: _____</p>	Ja	Nee
<p>Samenhangend met een andere neurobiologische ontwikkelings-, psychische of gedragsstoornis Zo ja, vermeld deze: _____</p>	Ja	Nee
<p>Met katatonie Zo ja, gebruik de aanvullende code 293.89 katatonie bij autismespectrumstoornis om de aanwezigheid van de comorbide katatonie aan te geven.</p>	Ja	Nee
<p>7. Context De informatie verkregen met de NIDA is gewogen in de context. Zo ja, vermeld met welk(e) onderzoek(en): <input type="checkbox"/> Brede klinische psychodiagnostiek (intake) <input type="checkbox"/> Ontwikkelingsanamnese <input type="checkbox"/> Heteroanamnese <input type="checkbox"/> Gedragsobservatie <input type="checkbox"/> Neuropsychologisch onderzoek <input type="checkbox"/> Persoonlijkheidsonderzoek <input type="checkbox"/> Intelligentieonderzoek <input type="checkbox"/> Psychiatrisch onderzoek <input type="checkbox"/> Somatisch onderzoek <input type="checkbox"/> Overig Zo ja, vermeld deze: _____</p>	Ja	Nee

<p>8. Differentiaaldiagnostische overweging De kenmerken kunnen niet beter verklaard worden door de aanwezigheid van een andere stoornis en/of omgevingsproblemen. Zo nee, vermeld deze: <input type="checkbox"/> Verstandelijke beperking <input type="checkbox"/> Sociale (pragmatische) communicatiestoornis <input type="checkbox"/> ADHD <input type="checkbox"/> Psychotische stoornis <input type="checkbox"/> Bipolaire-stemmingsstoornis <input type="checkbox"/> Depressieve-stemmingsstoornis <input type="checkbox"/> Sociale-angststoornis <input type="checkbox"/> Gegeneraliseerde-angststoornis <input type="checkbox"/> Obsessieve-compulsieve stoornis <input type="checkbox"/> Trauma- of stressgerelateerde stoornis <input type="checkbox"/> Dissociatieve stoornis <input type="checkbox"/> Somatisch-symptoomstoornis <input type="checkbox"/> Voedings- of eetstoornis <input type="checkbox"/> Disruptieve, impulsbeheersings- of andere gedragsstoornis <input type="checkbox"/> Middelgerelateerde of verslavingsstoornis <input type="checkbox"/> Neurocognitieve stoornis <input type="checkbox"/> Persoonlijkheidsstoornis Zo ja, vermeld deze: _____ _____ <input type="checkbox"/> Onveilige hechting <input type="checkbox"/> Misbruik/mishandeling/verwaarlozing <input type="checkbox"/> Lichamelijke ziekte <input type="checkbox"/> Overige stoornissen/problemen Zo ja, vermeld deze: _____ _____</p>	Ja	Nee
<p>9. DSM-5-classificatie ASS</p>	Ja	Nee
<p>Vastgesteld door: _____ Functie: <input type="checkbox"/> Gezondheidszorgpsycholoog <input type="checkbox"/> Klinisch psycholoog <input type="checkbox"/> Klinisch neuropsycholoog <input type="checkbox"/> Psychiater <input type="checkbox"/> Verpleegkundig specialist</p>		
<p>10. Mate van actuele ernst van de beperking is gespecificeerd (zie p. 26). Zo ja, specificeer de mate van actuele ernst voor sociale communicatie: <input type="checkbox"/> Niveau 3 'Vereist zeer substantiële ondersteuning' <input type="checkbox"/> Niveau 2 'Vereist substantiële ondersteuning' <input type="checkbox"/> Niveau 1 'Vereist ondersteuning'</p>	Ja	Nee
<p>Zo ja, specificeer de mate van actuele ernst voor beperkt, repetitief gedrag: <input type="checkbox"/> Niveau 3 'Vereist zeer substantiële ondersteuning' <input type="checkbox"/> Niveau 2 'Vereist substantiële ondersteuning' <input type="checkbox"/> Niveau 1 'Vereist ondersteuning'</p>		

Formulier voor mate van actuele ernst van de autismespectrumstoornis

Mate van ernst: niveau 3

'Vereist zeer substantiële ondersteuning'

Sociale communicatie	Ja	Nee
Ernstige deficiënties in de verbale en non-verbale sociale-communicatievaardigheden veroorzaken ernstige beperkingen in het functioneren,	Ja	Nee
zeer beperkte initiatieven tot sociale interacties	Ja	Nee
en een minimale reactie op sociale-toenaderingspogingen van anderen. <i>De betrokkene spreekt bijvoorbeeld slechts enkele verstaanbare woorden en neemt zelden het initiatief tot sociale interactie, en als hij of zij dat wel doet, benadert hij of zij de ander op een ongewone manier, alleen om aan eigen behoeften te voldoen, en reageert hij of zij alleen op een zeer directe sociale toenadering.</i>	Ja	Nee
Beperkt, repetitief gedrag	Ja	Nee
Er is sprake van inflexibel gedrag, extreme moeite met het omgaan met veranderingen, of ander beperkt, repetitief gedrag dat duidelijk het functioneren op alle levensgebieden belemmert.	Ja	Nee
De betrokkene heeft verhoogde stress door of grote moeite met het veranderen van de focus of de handeling.	Ja	Nee

Mate van ernst: niveau 2

'Vereist substantiële ondersteuning'

Sociale communicatie	Ja	Nee
Duidelijke deficiënties in de verbale en non-verbale sociale-communicatievaardigheden;	Ja	Nee
duidelijk zichtbare sociale beperkingen, ondanks aanwezige ondersteuning;	Ja	Nee
beperkte initiatieven tot sociale interacties;	Ja	Nee
en verminderde of abnormale reacties op sociale-toenaderingspogingen van anderen. <i>De betrokkene spreekt bijvoorbeeld alleen in eenvoudige zinnen, de interactie blijft beperkt tot zeer gelimiteerde interesses en de betrokkene vertoont een duidelijk vreemde non-verbale communicatie.</i>	Ja	Nee
Beperkt, repetitief gedrag	Ja	Nee
Inflexibel gedrag, moeite om met verandering om te gaan of ander beperkt, repetitief gedrag	Ja	Nee
komt vaak genoeg voor om de toevallige waarnemer op te vallen	Ja	Nee
en verstoort het functioneren in verschillende situaties.	Ja	Nee
De betrokkene heeft verhoogde stress door of grote moeite met het veranderen van de focus of de handeling.	Ja	Nee

Mate van ernst: niveau 1

'Vereist ondersteuning'

Sociale communicatie	Ja	Nee
Zonder ondersteuning veroorzaken de deficiënties in de sociale communicatie merkbare beperkingen.	Ja	Nee
De betrokkene heeft moeite met het initiëren van sociale interacties	Ja	Nee
en er zijn duidelijke voorbeelden van atypische of onsuccesvolle reacties op de sociale-toenaderingspogingen van anderen.	Ja	Nee
De betrokkene kan verminderde belangstelling hebben voor sociale interacties. <i>Hij of zij kan bijvoorbeeld volzinnen uiten en deelnemen aan de communicatie, maar slaagt er niet in om een over-en-weergesprek met anderen te voeren, en zijn of haar pogingen om vriendschap te sluiten zijn vreemd en blijven zonder resultaat.</i>	Ja	Nee
Beperkt, repetitief gedrag	Ja	Nee
Inflexibel gedrag vormt een significante verstoring in het functioneren in een of meer situaties.	Ja	Nee
De betrokkene heeft moeite met het overschakelen op andere activiteiten.	Ja	Nee
Problemen met organiseren en plannen staan onafhankelijkheid in de weg.	Ja	Nee

**Nederlands Interview ten behoeve van Diagnostiek
Autismespectrumstoornis bij volwassenen (NIDA)**

Eerste druk: september 2014

Tweede ongewijzigde druk: juli 2016

Ontwikkeling en uitgave van de NIDA zijn mogelijk gemaakt door Sarr Expertisecentrum Autisme - Bavo-Europoort en Lucertis - onderdeel van Parnassia Groep.

Met dank aan de volgende collega's voor hun inhoudelijke en tekstuele adviezen:

- Mathijs Deen, statisticus, Parnassia Groep
- Michiel Hengeveld, psychiater en emeritus hoogleraar psychiatrie, Erasmus MC
- Pieter de Nijs, kinder- en jeugdpsychiater, Erasmus MC - Sophia en Sarr Expertisecentrum Autisme

De NIDA is in een tweede oplage van 1000 exemplaren en een pdf-bestand kosteloos beschikbaar. De NIDA mag niet gebruikt worden voor commerciële doeleinden.

Deze uitgave is met zorg samengesteld. Onderdelen van deze uitgave kunnen in de loop van de tijd veranderen. U kunt geen rechten ontlenen aan deze uitgave. Meer informatie over en toekomstige wijzigingen van de NIDA kunt u opvragen bij de auteur.

Vormgeving en druk: Anneloes van den Berg, Dare to Design Rotterdam.

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Appendix 2 - NIDA
(English version under construction)

NIDA
Dutch Interview for Diagnostic assessment of Autism spectrum
disorder in adults

Richard Vuijk

Nederlands
Interview ten behoeve van
Diagnostiek
Autismespectrumstoornis bij volwassenen

2020

Name of the client:

Date of birth:

Age: ... years

Sex: male/female

Date of assessment:

Name of researcher:

Job title of researcher: Psychologist
 Health care psychologist
 Clinical psychologist
 Clinical neuropsychologist
 Psychotherapist
 Psychiatrist
 Specialist nurse

Person assessed: Client
 Partner
 Family member
if interviewed

Guardian/mentor/coach

Additional information:
.....
.....
.....

Note 1

When administering the NIDA to informants other than the client, the way the questions are formulated needs to be adjusted, for example 'Are you...' becomes 'Is...' etc.

Note 2

In the examples mentioned for questions 2 and 3, 'atypical' can be interpreted as deviating from average.

Advice

When more than one informant is involved in the assessment, you could choose to use different colours for each informant when filling in the answers and scores on the questionnaire and answer forms, for example black for the client and blue for the partner.

Question 1

DSM-5-ASD-criterion A: Symptom 1

Do you think that you are impaired in making contact with others and in sharing thoughts and feelings, for example by having to keep calculating what is socially intuitive to others?

(Do you think that you are impaired in making contact with others? Do you think that you are impaired in sharing thoughts and feelings? For example by having to keep calculating what is socially intuitive to others.)

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Having to keep calculating what is socially intuitive to others (when and how to enter a conversation; what is appropriate/ inappropriate to say)
- Unable to start, respond to or keep social interactions going
- Limited ability or unable to engage in back and forth conversation (monologue, talking over others)
- A lack of social reciprocity in language and speech: making requests or labelling but not engaging in conversation
- Only responding from one's own point of view or experience
- Not adjusting to or taking others and their emotions into account
- Limited ability or a lack of sharing and understanding emotions (happy, scared, angry, sad)
- Limited or no sharing of interests
- Poor social reciprocity in conversations and good at topical discussions
- After using strategies to compensate, social problems persist in new situations or in situations where there is no support
- Other:

Examples during childhood

- Showing limited or no initiative regarding social interaction
- Approaching others in an unusual way (clearly deviating from what is commonly accepted and age appropriate)
- Only responding to a very direct social approach
- Only approaching others to meet one's own needs
- Limited or lack of imitation of behaviour of others
- Limited or no sharing of interests

- Limited ability or unable to engage in back and forth conversation (monologue about specific topics; talking over others)
- A lack of social reciprocity in language and speech: making requests or labelling, but not engaging in conversation
- Limited ability or a lack of sharing and understanding emotions (happy, scared, angry, sad)
- Difficulty assessing when and how social-emotional responses are appropriate (laughing when another child is showing sadness; can come across as cocky, blunt and tactless)
- Comes across as emotionally less mature than their peers
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 2

DSM-5-ASD-criterion A: Symptom 2

Do you think that you are impaired in your non-spoken way of communicating, such as using eye contact? (When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Lack of, limited and/or atypical use of eye contact (not making eye contact, staring, looking through the other person)

- Lack of, limited and/or atypical use of gestures (not describing and not expressing with hands in communication; difficulty to spontaneously use expressive gestures in communication)
- Lack of, limited and/or atypical use of facial expressions
- Lack of, limited and/or atypical use of body language (strange, stiff or exaggerated body language)
- Limited or lack of 'reading' and responding to eye contact, gestures, facial expressions, and/or body language of others
- Understanding facial expressions rationally instead of intuitively
- Abnormal intonation in speech, unsuited to the content of the conversation (slow, fast, loud, soft, insistent, unclear, not adjusted)
- Relatively few limitations, but an obvious poor integration of eye contact, gestures, facial expressions, body posture and rhythm, emphasis and intonation of the voice for the purpose of social communication
- Other:

Examples during childhood

- Lack of, limited and/or atypical use of eye contact (not making eye contact, staring, looking through the other person)
- Lack of, limited and/or atypical use of gestures (not describing and not expressing with hands in communication; difficulty to spontaneously use expressive gestures in communication)
- Lack of, limited and/or atypical use of facial expressions (at 12 months not smiling reciprocally)
- Lack of, limited and/or atypical use of body language (strange, stiff or exaggerated body language)
- Limited ability regarding shared attention (not pointing at, showing or bringing along objects to share interests with others, unable to follow a pointed finger or directed gaze of others)
- Limited or lack of 'reading' and responding to eye contact, gestures, facial expressions, and/or body language of others
- Abnormal intonation in speech, unsuited to the content of the conversation (slow, fast, loud, soft, insistent, unclear, not adjusted)
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 3

DSM-5-ASD-criterion A: Symptom 3

Do you think that you are impaired in starting, maintaining, and understanding relationships, for example rigidly holding onto social etiquette?

(Do you think that you are impaired in starting relationships? Do you think that you are impaired in maintaining relationships? Do you think that you are impaired in understanding relationships? For example rigidly holding onto social etiquette.)

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Social behaviour comes across as learned (rigidly holding onto social etiquette; formal)
- Lack of, limited and/or atypical social interest (rejecting others, passivity or an inappropriate treatment of others that can seem aggressive or disturbing)
- The relationship with others does not progress, stays superficial (no development in social interactions, no response to social overtures from others)
- Difficulty starting and maintaining friendships (no realistic awareness of the meaning of friendship; one sided friendship; friendship solely based on a shared interest)
- No interest in peers
- No interest in social relationships (instrumental/formal contact)
- Preference to be alone, to live alone (contact is seen as unnecessary, unpleasant, stressful, tiring, loner)

- Limited or lack of understanding of what is appropriate behaviour in different situations/relationships (home versus work; casual behaviour during job interviews)
- Limited or lack of understanding the diverse use of language (irony, white lies, humour, fantasy, pretending, taking things literally)
- Other:

Examples during childhood

- Social behaviour comes across as learned (rigidly holding onto social etiquette; formal)
- Lack of, limited and/or atypical social interest (rejecting others, passivity or an inappropriate treatment of others that can seem aggressive or disturbing)
- Lack of, limited and/or atypical social play and fantasy play (insisting on playing games alone with clearly fixed rules; not being able to play a role)
- The relationship with others does not progress, stays superficial (no development in social interactions; seems 'deaf'; at 12 months no 'social interactive' babbling, no response to social overtures from others)
- Difficulty starting and maintaining friendships (one sided friendship; friendship solely based on a shared interest)
- No interest in peers
- No interest in social relationships (instrumental contact)
- Preference to be alone, to live alone (contact is seen as unnecessary, unpleasant, stressful, tiring, living in their own world)
- Limited or lack of understanding the diverse use of language (humour, fantasy, pretending, taking things literally)
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 4

DSM-5-ASD-criterion B: Symptom 1

Do you have a typical or repetitive way of moving, of using objects, or of speaking, for example moving your body up and down, putting objects in order, or literally repeating the words of others?

(Do you have a typical or repetitive way of moving, for example moving your body up and down? Do you have a typical or repetitive way of using objects, for example putting things in order? Do you have a typical or repetitive way of speaking, for example literally repeating the words of others?)

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Moving in a typical or repetitive way (moving body up and down, flapping the arms and hands, snapping fingers)
- Using objects in a typical or repetitive way (not functional; flipping objects; putting things in order)
- Having a typical or repetitive way of speaking (making up new words or expressions; literally or as precisely as possible repeating sounds, words or sentences of others, immediately or delayed; formal and old fashioned use of language; using 'you' when speaking about oneself)
- Other:

Examples during childhood

- Moving in a typical or repetitive way (moving body up and down, flapping the arms and hands, spinning on one's axis)
- Using objects in a typical or repetitive way (lining up toys; flipping objects)
- Having a typical or repetitive way of speaking (making up new words or expressions; literally or as precisely as possible repeating sounds, words or sentences of others, immediately or delayed; formal and old fashioned use of language; using 'you' when speaking about oneself)
- Other:

Symptom present in current functioning:

Client Yes ? No Not asked

Partner Yes ? No Not asked

Family member Yes ? No Not asked

Guardian Yes ? No Not asked

Symptom present in childhood:

Client Yes ? No Not asked

Partner Yes ? No Not asked

Family member Yes ? No Not asked

Guardian Yes ? No Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 5

DSM-5-ASD-criterion B: Symptom 2

Are you insistent on sameness? Do you have rigid (inflexible) routines or ritualised patterns in your manner of speaking or behaving, for example resistance to change?

(Are you insistent on sameness? Do you have rigid (inflexible) routines? Do you have ritualised patterns in your manner of speaking? Do you have ritualised patterns in your way of behaving? For example resistance to change.)

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Resistance to change (extreme distress/tension when change occurs e.g. in time, order, surroundings, activities, appointments; experiencing great difficulty with change)
- Difficulties with transitions (e.g. moving house, changing jobs, daylight saving, change of seasons, holidays)
- Rigid thinking patterns (rule is rule; law is law; a deal is a deal)

- Rigid routines or ritualised patterns (a need to do activities in a specific order and at a specific time; a need to always take the same route; pacing back and forth; every day the same food; greeting others overly formal or extensively; repeatedly asking questions)
- Other:

Examples during childhood

- Resistance to change (extreme distress/tension when change occurs e.g. in time, order, surroundings, activities, appointments; experiencing great difficulty with change)
- Difficulties with transitions (e.g. moving house, moving to the next class, daylight saving, change of seasons, holidays)
- Rigid thinking patterns (rule is rule; law is law; a deal is a deal)
- Rigid routines or ritualised patterns (a need to do activities in a specific order and at a specific time; a need to always take the same route; pacing back and forth; every day the same food; greeting others overly formal or extensively; repeatedly asking questions)
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning:	Yes	?	No
Symptom present in early developmental period (childhood):	Yes	?	No

Question 6

DSM-5-ASD-criterion B: Symptom 3

Do you have highly restricted, fixated interests which are extreme in intensity or focus, for example intensively collecting information about a subject?

(Do you have highly restricted, fixated interests which are extreme in intensity? Do you have highly restricted, fixated interests which are extreme in focus? For example intensively collecting information about a subject).

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- A very strong preference to be occupied with (un)usual objects or information (collecting, ordering, studying, fantasising)
- Highly restricted interests (for only one topic, activity)
- Pervasive, persistent interests (in terms of time spent on them, not being able to stop on time)
- Special interests which may seem strange to others
- Being occupied with these interests hinders social interaction and daily functioning
- Time spent on these interests increases in times of stress and tension
- Being occupied with these interests reduces tension (is relaxing)
- Being occupied with these interests comes across as compulsive
- Disturbance by others with these interests leads to confusion, irritation, anger, anxiety or tension
- Other:

Examples during childhood

- A very strong preference to be occupied with (un)usual objects or information (collecting, ordering, studying, fantasising)
- Highly restricted interests (for only one topic, activity)
- Pervasive, persistent interests (in terms of time spent on them, not being able to stop on time)
- Special interests which may seem strange to others
- Being occupied with these interests hinders social interaction and daily functioning
- Time spent on these interests increases in times of stress and tension
- Being occupied with these interests reduces tension (is relaxing)

- Being occupied with these interests comes across as compulsive
- Disturbance by others with these interests leads to confusion, irritation, anger, anxiety or tension
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 7

DSM-5-ASD-criterion B: Symptom 4

Are you hyper- or hyporeactive to sensory input, or do you have an unusual interest in sensory aspects of the environment, for example for sound, light, or scent?

(Are you hyper- or hyporeactive to sensory input? Or do you have an unusual interest in sensory aspects of the environment? For example sound, light or scent.)

(When answered 'yes':) Can you give an example?

And how was that during childhood?

Examples current functioning

- Indifferent to and/or not sensing and recognising pain, temperature, sound, light, scent
- Hypersensitive to and/or extreme reaction to pain, temperature, light, scent, food, fabrics
- Visual fascination/ perception of detail (light, movement)

- Auditory fascination/ perception of detail (sound, musical tones)
- Unable to tolerate being touched by others or undergoing this with great difficulty
- Excessively smelling or touching objects or people
- Other:

Examples during childhood

- Indifferent to and/or not sensing and recognising pain, temperature, sound, light, scent
- Hypersensitive to and/or extreme reaction to pain, temperature, light, scent, food, fabrics
- Visual fascination/ perception of detail (light, movement)
- Auditory fascination/ perception of detail (sound, musical tones)
- Unable to tolerate being touched by others or undergoing this with great difficulty
- Excessively smelling or touching objects or people
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning: Yes ? No

Symptom present in early developmental period (childhood): Yes ? No

Question 8

DSM-5-ASD-criterion D

In which areas do you experience distress, or do you think that you are impaired in your ability to function due to the aforementioned symptoms, for example at work?

(In which areas do you experience distress due to the aforementioned symptoms? In which areas do you think that you are impaired in your ability to function due to the aforementioned symptoms? For example at work).

And how was that during childhood?

Examples current functioning

- Relationship/Family
- Family (in which you were raised)
- Social contacts, friends, acquaintances
- Work/daily activities/education
- Free time, hobby, sports
- Self-esteem/self-image
- Little to no impairment due to support, compensating behaviour or learned interventions (with great effort of those involved in order to function as optimal as possible)
- Other:

Examples during childhood

- Family
- Family (in which you were raised)
- Social contacts, friends, acquaintances
- Kindergarten/nursery school/primary school
- Free time, hobby, sports, play
- Self-esteem/self-image
- Little to no impairment due to support, compensating behaviour or learned interventions (with great effort of those involved in order to function as optimal as possible)
- Other:

Symptom present in current functioning:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

Symptom present in childhood:

Client	Yes	?	No	Not asked
Partner	Yes	?	No	Not asked
Family member	Yes	?	No	Not asked
Guardian	Yes	?	No	Not asked

In conclusion

Symptom present in current functioning:	Yes	?	No
Symptom present in early developmental period (childhood):	Yes	?	No

NIDA

Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults

Author: Richard Vuijk

www.sarr.nl

www.autismespectrumnederland.nl

English version of *Nederlands Interview ten behoeve van Diagnostiek Autisme-spectrumstoornis bij volwassenen* by Richard Vuijk (first printing 2014, second printing 2016).

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List of Abbreviations

AD	Autistic Disorder
AdAS	Adult Autism Subthreshold Spectrum
ADHD	Attention-Deficit/Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview – Revised
ADOS-G	Autism Diagnostic Observation Schedule – Generic
ADOS-2	Autism Diagnostic Observation Schedule – Second Edition
AIC	Akaike Information Criterion (Statistics)
APA	American Psychiatric Association
AQ	Autism Spectrum Quotient
AR1	Autoregressive (Statistics)
ARMA	Autoregressive-moving-average (Statistics)
AS	Asperger’s Disorder
ASD	Autism Spectrum Disorder
BAP	Broader Autism Phenotype
BFI	Big Five Inventory
BIC	Bayesian Information Criteria (Statistics)
BPD	Borderline Personality Disorder
CBT	Cognitive Behavioral Therapy
CDC	Centers for Disease Control and Prevention
CO	Cooperativeness (TCI)
COM	Comparison Group
CONSORT	Consolidated Standards of Reporting Trials
DAPP-BQ	Dimensional Assessment of Personality Pathology – Basic Questionnaire
DSM-III	Diagnostic and Statistical Manual of Mental Disorders Third Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision
DSM-5	Diagnostic and Statistical Manual of Mental Disorders Fifth Edition
EPQ	Eysenck Personality Questionnaire
Exp	Experiential
FFM	Five-Factor Model
HA	Harm Avoidance (TCI)
HFA	High-Functioning Autism
IQ	Intelligence Quotient
IPDE	International Personality Disorder Examination
IPIP-NEO-120	International Personality Item Pool Representation of the NEO-PI-R
MANOVA	Multivariate Analysis of Variance (Statistics)

MEC	Medical Ethics Committee
MMPI-2	Minnesota Multiphasic Personality Inventory – Second edition
NCCMH	National Collaborative Centre for Mental Health
NIDA	Dutch Interview for Diagnostic assessment Autism spectrum disorder in adults (<i>Nederlands Interview ten behoeve van Diagnostiek Autismspectrumstoornis bij volwassenen</i>)
NCC	Non-Clinical Controls
NEO	Neuroticism, Extraversion, Openness to Experience
NEO-FFI	NEO Five-Factor Inventory
NEO-PI-R	NEO-Personality Inventory-Revised
NPD	Narcissistic Personality Disorder
NS	Novelty Seeking (TCI)
N.S.	Not Significant (Statistics)
PD(s)	Personality Disorder(s)
PDNOS	Personality Disorder Not Otherwise Specified
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PS	Persistence (TCI)
PSY-5	Personality Psychopathology-Five
PTSD	Posttraumatic Stress Disorder
RCT	Randomized Controlled Trial
RD	Reward Dependence (TCI)
SAM	Standardized Assessment for Mental Disorders – A Semi-Structured Interview
SCID-II	Structured Clinical Interview for DSM-IV Axis-II Personality Disorders
SCID-II Screen	Structured Screening for DSM-IV Axis-II Personality Disorders
SCID-5-PD	Structured Clinical Interview for DSM-5 Personality Disorders
SCID-5-SPQ	Structured Clinical Interview for DSM-5 Personality Disorders - Self-Report Personality Questionnaire
SCL-90	Symptom Check List
SD	Self-Directedness (TCI)
SIS(s)	Social Interaction Style(s)
SMI	Schema Mode Inventory
SPQ	Schizotypal Personality Questionnaire
SPSS	Statistical Package for the Social Sciences
SRS-A	Social Responsiveness Scale – Adult Version
SSP	Swedish Universities Scales of Personality
ST	Self-Transcendence (TCI)

ST	Schema Therapy
ST-MASC	Schema Therapy Modified for Autism Spectrum Conditions
SUD	Substance Use Disorder
TAU	Treatment-As-Usual
TCI	Temperament and Character Inventory
TD	Typically Developing
VAS	Visual Analogue Scale
VTCT	Short Version of Temperament and Character Inventory

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My name is Richard Vuijk, born in 1973 in Rotterdam, the Netherlands. After graduating for my secondary education at the Roman Catholic Sint-Montfortcollege, Rotterdam, I studied Orthopedagogiek at Leiden University, the Netherlands. During my work at Sarr Autism Rotterdam, part of Parnassia Psychiatric Institute, the Netherlands, I studied postgraduate health care and clinical psychology.

I am a clinical psychologist, and my focus is treating mental health problems in adults with autism spectrum disorder. My research and publications address the assessment, personality (pathology), and treatment of individuals with autism spectrum disorder. In 2018 I was awarded the Jeffrey Young Investigator Award in recognition of high research standards for our Schema Therapy study. I am active in the training of psychologists and psychiatrists to diagnose and treat autism spectrum disorder and personality pathology in adults. In 2014 (second edition 2016) I developed the NIDA – Dutch Interview for Diagnostic assessment of Autism spectrum disorder in adults.



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