Description and measurement of sensory symptoms in autism spectrum

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Description and measurement of sensory symptoms in autism spectrum

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Abstract

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Unusual responses to sensory stimuli have been reported in nearly all children with autism spectrum conditions (ASC). A few studies on adults indicate that the sensory and perceptual problems persist into adulthood. Sensory symptoms have not been included in the diagnostic criteria for ASC but in the new diagnostic manual (DSM-5, 2013) hyper- or hyporeactivity or unusual sensory interests were included in the diagnostic criteria for ASC. Sensory phenomena are mostly investigated in studies involving children and the scales used to measure sensory reactivity have been constructed on the basis of the scientific literature and parents' reports. The experiences of adults with ASC are not well understood and have not been systematically used to develop measures.

The overall aim of the thesis was to capture the first-hand experiences of and perspectives on sensory reactivity and translate them into a self-rating scale. To fulfil this overarching aim the personal sensory experiences of adults with ASC were investigated and the variations and range of atypical sensory phenomena explored and described in two qualitative studies (study I and II). The analyses of the first-person descriptions enabled the development of items for a scale. These were reduced in steps and the final scale which was named the Sensory Reactivity in Autism Spectrum scale (SR-AS) comprised 32 items in four subscales: high awareness/hyperreactivity, low awareness/hyporeactivity, strong sensory interests and sensory/motor. The SR-AS was validated using content and factor analyses. Its discriminative validity was then investigated as well as its reliability in the form of internal consistency (study III). In the final step the scale was used to identify clusters of atypical sensory functioning in adults with ASC by hierarchical cluster analysis (study IV). Three different sensory clusters were found.

The main contribution of this thesis is its presentation of individual experience and perspectives and the creation of an clinical tool to measure atypical sensory reactivity frequently experienced by people with ASC. The ways in which the SR-AS can be used comprise assessment of individual sensory patterns for self-knowledge and awareness, to enable the development of coping strategies and to provide information on environmental adjustments required. In diagnostic processes where other criteria for ASC are fulfilled the SR-AS can be used for assessing sensory symptoms according to the DSM-5.

Keywords: Autism spectrum, sensory, perception, qualitative research, scale development, scale validation, sensory clusters.

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LIST OF PAPERS

This thesis is based on the following original papers which are referred to in the text by their Roman numerals:

- I. Elwin M., Ek L., Schröder A., Kjellin L. (2012). Autobiographical accounts of sensing in Asperger syndrome and high functioning autism. Archives of Psychiatric Nursing, 26, 420-429.
- II. Elwin M., Ek L., Kjellin L., Schröder A. (2013). Too much or too little: Hyper- and hypo-reactivity in high functioning autism spectrum conditions. Journal of Intellectual and Developmental Disability, 38, 232-241.
- III. Elwin M., Schröder A., Ek L., Kjellin L. (2016). Development and pilot validation of a sensory reactivity scale for adults with high functioning autism spectrum conditions: Sensory Reactivity in Autism Spectrum (SR-AS). Nordic Journal of Psychiatry, 70, 103-110.
- IV. Elwin M., Schröder A., Ek L., Wallsten T., Kjellin L. Sensory clusters of adults with and without autism spectrum conditions. Submitted.

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LIST OF ABBREVIATIONS

ADHD Attention deficit hyperactivity disorder

ADD Attention deficit disorder

ADI-R Autism Diagnostic Interview Revised ADOS Autism Diagnostic Observation Scale

AMOS Analysis of moment structures
ASC Autism spectrum condition
ASD Autism spectrum disorder

ASDI Asperger Syndrome (and high functioning autism) Diagnos-

tic Interview

AQ Autism Spectrum Quotient AUC Area under the curve BAP Broader autism phenotype

CA Content analysis

CFA Confirmatory factor analysis

CMIN/DF Chi Square divided by its degrees of freedom

DISCO Diagnostic Interview for Social and Communication Disor-

der

DSM-IV- Diagnostic and Statistical Manual of Mental Disorders, 4th

TR ed. Text Revision

DSM-5 Diagnostic and Statistical Manual of Mental Disorders, 5th

ed.

EFA Exploratory factor analysis

ICD-10 International Classification of Diseases and Related Healt

Problems 10th Revision

PD-NOS Pervasive developmental disorder not otherwise specified

RMSEA Root mean square of approximation SRMR Standardized root mean square residual

TD Typically developed (no neurodevelopmental condition)

ToM Theory of mind

WCC Weak central coherence WHO World Health Organization

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INTRODUCTION

This thesis explores sensory reactivity in autism spectrum conditions (ASC) with focus on capturing firsthand experiences and perspectives and translating them into a self-rating scale. The introductory section provides a brief general introduction to ASC with an overview of diagnostic characteristics, epidemiology, aetiology, comorbidity, cognitive theories of and assessment instruments for autism. The general introduction is followed by a more detailed introduction and a review of sensory and perception issues in ASC.

My interest in the autism spectrum and sensory issues was aroused by encounters with patients with ASC diagnoses in my clinical work as a psychologist in adult psychiatric care. The patients described differences in sensations, perceptions, thoughts, relationships and intensity of interests. They conveyed experiences of varying degrees of weak connectedness to the outside world concurrent with lack of protection from it, due to lack of filters for incoming sensations and information. I wanted to understand this paradox from an interior perspective. Through my dialogue with patients before I started thinking in research terms I became aware of large differences between my perception and the perception described by the patients. It is not possible to know definitely how another person perceives something. The only way to get some of the picture is through communication. This thesis sprang from efforts to communicate and clinical considerations that turned into research questions and a search for a scientific approach. It is motivated by the desire to understand the actual experiences of people with ASC.

Introduction to autism spectrum conditions Classic writings on autism

The psychiatrist Leo Kanner (1943/1985) was the first to describe a group of children with "autistic disturbance of affective contact" (p.11) who all experienced "extreme autistic aloneness" (p. 41) from the beginning of life. According to his observations, the fundamental characteristic of these children was the inability to relate to people and situations from birth. Other characteristics were verbal and motion repetitions, a desire for maintenance of sameness, restricted spontaneous activity, inability to experience entireties without full attention to the constituent parts, a good relation to objects, excellent rote memory and literalness. Kanner also addressed sensory perceptual matters in the form of fearful reactions to

sound or touch and also what we would today call unusual sensory interests (e.g. spinning objects, fascination with reflecting light).

The paediatrician Hans Asperger (1944/1991) wrote independently at approximately the same time about a group of children who had a disturbed and limited interaction with their environment from the beginning of life. He pointed to their compensating assets, in the form of original lines of thought, special interests and excellent performance within circumscribed areas, whereas every-day functions were very poor. Stereotypical movements, habits and verbal utterances and the insistence on adherence to exactly the same routines and rituals were also observed.

The key feature in the accounts of both Asperger and Kanner is the limited social relatedness. Both noticed unusual sensory reactions as part of the condition although their respective understanding of the sensory issues differed. Kanner framed his description in a developmental context (Volkmar, Reichow, Westphal & Mandell, 2014). He identified evidence of deviations from typical development in the children he observed. Asperger's observations were similar but lacked the developmental frame that Kanner applied. Asperger's approach was educational, highlighting the need to meet these children in a way that would further learning. Kanner viewed unusual sensory reactions as connected to the prime characteristic of aloneness and isolation. He understood the sensory reactions as resulting from an experienced intrusion from the outer world that threatened the aloneness of the child. Kanner did not comment especially on the sensory quality of children's strong preoccupations with objects in their environment. In Asperger's account the sensory reactions are not as intertwined with isolation in a world of one's own but were understood more as unusual sensory reactions per see. He described the paradoxical over sensitivity and concurrent, striking lack of sensitivity when a child can shut out and ignore some sounds while at the same time remaining extremely sensitive to other sounds. He also gave examples of strong food/taste preferences and aversions as well as sensitivity to touch. The phenomena of paradoxical hyper- and hyporeactivity sometimes in the same modality was obvious already in Asperger's description. In general the early observations by Kanner and Asperger are still valid and cover most of the current activity in the research field of autism.

The concept of an autism spectrum

Wing and Gould (1979) discovered a broad spectrum of conditions with impairments of social interaction, language development and repetitive

activities rather than symbolic imaginative activities on different levels of intellectual functioning, with and without identifiable organic pathology. The concept of an autistic continuum with a range of ability and severity levels was later elaborated (e.g. Wing, 1988). The deficits in social interaction, in communication and in imaginative development were referred to as the "triad of impairments".

Autism spectrum diagnosis and definitions

The Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text rev. (DSM-IV-TR; APA, 2000) used a categorical system for diagnoses in the autism spectrum including autistic disorder, Asperger's disorder and pervasive developmental disorder not otherwise specified. These different categorical disorders were merged into a single diagnostic spectrum in the new edition of DSM (DSM-5; APA, 2013), namely autism spectrum disorder (ASD), or autism spectrum condition (ASC) which is the tem used in this thesis. I prefer this term because it acknowledges that there are both strengths and weaknesses in learning and information processing in ASC (Dawson & Mottron, 2011).

DSM-IV and ICD-10 (WHO, 1992) both include three dimensions of diagnostic characteristics for autism: deficits in social reciprocity, deficits in communication and restricted, repetitive behaviors and interests. The DSM-5 now defines autism by two dimensions: deficits in reciprocal social-communication and markedly restricted activities and interests (table 1). The social-communication dimension has three criteria: deficits in social-emotional reciprocity, in nonverbal communicative behaviors used for social communication and in developing and maintaining relationships. All three are required for the dimension to be fulfilled. The second dimension of restricted, repetitive behaviors and interests is defined by four criteria: verbal and non-verbal stereotyped and repetitive behaviors, rituals and insistence on sameness, fixated or excessively circumscribed interests and unusual reactions to sensory input. Two of these are required for the dimension to be fulfilled. The relation of hyper-hyporeactivity and sensory interests to the other features in the second DSM-5 dimension of ASC is not totally clear. Grapel, Cicchetti, & Volkmar (2015) point out the difficulty of separating sensory issues from restricted, repetitive behaviors/interest into different components.

Table 1 Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) autism spectrum criteria (exemplifications and specifications in the text are omitted)

- A. Persistent deficits in social communication and social interaction across multiple contexts
- 1. Deficits in social emotional reciprocity
- 2. Deficits in non-verbal communicative behaviors used for social interaction
- 3. Deficits in developing, maintaining and understanding relationships
- B. Restricted, repetitive patterns of behavior, interests or activities as manifested by at least two of the following
- 1. Stereotyped or repetitive motor movements, use of objects or speech
- 2. Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or non-verbal behavior
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus
- 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
- C. Symptoms must be present in the early developmental period
- D. Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning
- E. These disturbances are not better explained by intellectual disability

The DSM-5 builds on the idea of a continuum, a spectrum of severity and abilities as conceptualized by Wing (1988). Lately there has been research on a Broader Autism Phenotype (BAP) which denotes subclinical autistic-like traits outside the spectrum but similar to autism. Kanner as well as Asperger observed traits of social withdrawnness and preoccupations with intellectual, abstract subjects in the relatives of the children they described. Many years later the concept of BAP was coined to express the idea that the propensity for autism can be inherited in the form of traits that are qualitatively similar but milder than the diagnostic characteristics of ASC (e.g. Piven et al., 1994). Much research has been done in support of this idea. BAP characteristics are readily noticeable in first-degree relatives of individuals with ASC (Bailey et al., 1995; Piven et al., 1994). BAP features are also found in the general population (Constantino & Todd, 2003).

Aetiology of ASC

The autism spectrum is defined by complex neurodevelopmental differences and genetic factors play an important role. Early estimates of heritability from family and twin studies showed genetic factors to be substantial in ASC (Folstein & Rutter, 1977; Ritvo et al., 1985). A recent British twin study (Colvert et al., 2015) showed that both ASC and milder autistic traits are largely caused by genetic factors with heritability estimates of 56-95%. The aetiology is not fully understood and research is ongoing on the genetic neuroanatomical and neurophysiological underlying factors.

ASC is no longer considered by some researchers to be a single modular social cognitive deficit (Happé, 2003). ASC is consequently conceptualized as a multifactorial disorder. Happé and Ronald (2008) argue for a "fractionable autism triad". Thus the social, the communicative, and the restricted/repetitive behaviors and interests triad of symptoms cannot be explained by a single cause at the genetic, neural or cognitive level (Brunsdon & Happé, 2014). Instead it is suggested they should be viewed as separable and therefore better studied independently rather than as aspects of an overall cohesive syndrome.

Epidemiology of ASC

The overall prevalence of ASC was recently estimated to 1,47 per 100 or one in 68 children aged 8 years (Centers for Disease Control and Prevention [CDC], 2014). Another current, more conservative estimate is 0.66% or 1 child in about 152 children (Hill, Zuckerman & Fombonne, 2014). This is a huge increase from previous estimates of 4 per 10000 fifty years ago (Rutter, 2005). The increasing prevalence and incidence rates over time is probably due to a broader case definition and diagnostic substitution, in conjunction with greater access to services and higher awareness in the lay and professional public (Hill et al., 2014).

Autism affects more males than females with an average male-female ratio in epidemiological studies of 4,3 to 1 and can occur at all levels of intellectual ability. The percentage of people with ASC who are low functioning is increasingly lower in recent samples of people representing the full spectrum. In the CDC prevalence measurements, the proportion of children with intellectual ability in the average or above average range has increased over time from 32% in 2002 to 38% in 2006 and to 46% in 2010.

Prevalence of BAP

In recent research the prevalence of subclinical autistic traits ranged from 14-23 % for parents of children with ASC diagnoses and from 5-9 % in a community based comparison sample (Sasson et al., 2013). Consequently autistic-like traits can be assumed to be relatively prevalent in the general population.

Psychiatric comorbidity with ASC

Assessing ASC with adults in psychiatric settings is seldom a question of distinguishing individuals with ASC from typically developed persons (TDs), but of differentiating ASC from other psychiatric diagnoses (Eriksson, Andersen, & Bejerot, 2013). It is often complicated to assess first, whether an ASC or a differential diagnosis best covers the symptom manifestations, and second, whether all symptoms are aspects of an ASC or if a comorbid disturbance should be considered. Study results on prevalence rates of psychiatric comorbidity in adults with ASC vary greatly. Rates are high in samples of psychiatrically referred adolescents and adults (Hofvander, Delorme, Chaste, Nydén, Wentz, Stahlberg, et al., 2009; Lugnegård,, Hallerbäck,, & Gillberg 2011). In these studies the majority of people with ASC had at least one psychiatric comorbid diagnosis. In studies involving other types of samples the proportion is smaller with a range of 20% (Hutton et al., 2008) to around 30% experiencing severe mental health problems (Moss et al. 2014).

There is greater consensus on what the most common comorbid psychiatric disturbances are with ASC (Moss et al., 2014). In studies of psychiatrically referred adolescents or adults with ASC, the rates of lifetime prevalence of reported mood disorders were 50-77%, anxiety disorders around 50% and ADHD symptoms around 30- 40%. Rates for obsessive compulsive disorder were around 10-25%, psychotic disorders 5-13% and eating disorders around 5% (e.g. Hofvander et al., 2009; Lugnegård et al., 2011).

It is important to consider carefully whether manifested symptoms should be viewed as part of the ASC itself or as manifestations of a comorbid diagnosis. For example a tendency to overly focus on distressing stimuli and difficulty with shifting to a more positive affect can be part of the ASC or a manifestation of a mood disorder (Mazefsky Pelphrey & Dahl 2012). Sensory issues for example strong reactions to sensory stimuli or overload reactions could, of course, also be misinterpreted as symptoms unrelated to the ASC, e.g. anxiety symptoms. Moreover psychiatric disturbances may have a different presentation in ASC. For example decreased adaptive functioning and increased self-injury, repetitive behaviours and changes in preoccupations and interests to more morbid themes, may be manifestations of a mood disorder (Magnuson & Constatino 2011). Mazefsky et al., (2013) caution against overuse of comorbid diagnoses, when symptoms can be conceptualized as part of the ASC, or may stem from the general problem with regulation of emotions in ASC.

Cognitive theories of ASC

On a cognitive level three often cited models are proposed to explain autism. The theory of mind and the weak central coherence hypotheses are more specific to ASC than the executive dysfunction hypothesis. Deficits in executive functions are associated with many other conditions and disorders.

The theory of mind hypothesis

The "theory of mind" concept (ToM) was introduced by Premack and Woodruff (1978) who studied chimpanzees. They defined theory of mind as the ability to impute mental states to oneself and to others. Baron-Cohen, Leslie and Frith (1985) first raised the question of ToM in autism. ToM was originally studied in a developmental context and used to denote a categorical high-level mindreading capacity that TD children develop from around the age of four. It is now often used as a dimensional concept, the equivalent of mentalizing, meaning being able to represent mental states as defined by Baron-Cohen (2000) i.e. the ability to "infer the full range of mental states (beliefs, desires, intentions, imagination, emotions, etc.) that cause action. In brief, having a theory of mind is to be able to reflect on the contents of one's own and other's minds" (p. 3). ToM is the capability to disregard one's own perspective and adopt the perspective of the other. This ability makes it possible to foresee other people's actions. ToM thus covers ability to perceive one's own and other's state of mind and to be able to connect state of mind and action, so that actions can be foreseen and explained. There is extensive research on ToM in ASC (see Baron Cohen, 2000 for a review). There is a link between ToM and sensory perceptual differences through deficient joint attention i.e. less ability to coordinate ones attention to an object or to an event with another person (Mundy, 2003). It involves the ability to use eye contact to initiate joint attention and the ability to follow gaze in order to respond to it (Mundy & Newell, 2007). Joint attention is considered a building block of ToM (Baron-Cohen, et al. 1995; Mundy Sigman, Ungerer & Sherman, 1986). A simplified summation of the link between sensory perceptual differences and ToM would be (the sign> should be interpreted as "leads to"): Sensory and perceptual differences including regulation of attention > decreased capacity to calibrate into the attentional focus of another person > shared attention deficit > precursor of ToM and understanding other minds.

The executive dysfunction hypothesis

A persons executive functions (EFs) consist of "those capacities that enable a person to engage successfully in independent, purposive, self-serving behavior" (Lezak, Howieson & Loring, 2004 p. 35). Consequently executive dysfunction tend to have global effects on all aspects of behaviour (ibid). Executive functions are connected to prefrontal regions of the brain and comprise functions such as planning, initiation, working memory, impulse control, inhibition and mental flexibility and monitoring action (Hill, 2004). Hill points out that executive dysfunction in ASC is often found in planning and mental flexibility (a ready capability to adapt to new, different, or changing requirements), while results for inhibition and self-monitoring deficits are mixed. There is a direct connection between the second domain of restricted, repetitive and stereotyped patterns of behaviour in ASC and EFs for example lack of flexible adaption to novel situations (EF function). Deficiency in EFs therefore is linked to insistence on sameness in ASC (Kanner, 1943). Problems in adapting quickly and flexibly helps to explain the preference for predictability, routines and repetition expressed in the second dimension of the autism spectrum criteria in DSM-5. An illustration of the association of EFs with sensory processing would be: Problems with shifting focus (EF function) > difficult to become disentangled from a sensation or perception > highly focused attention to sensory details.

The weak central coherence hypothesis

The concept of central coherence was coined by Frith (1989) and refers to a natural tendency to assemble items of information to provide context and global meaning (seeing the forest, not just the trees). Frith suggested that this tendency is diminished in individuals with ASC. Information processing in ASC is assumed to be biased towards local processing over global processing, resulting in weak central coherence, i.e. a weak natural tendency to process items of information to attain coherence. The assumption is that people with ASC have a detail-focused cognitive style. The artist Peter Mayers describes a concentration on the specific as opposed to concentration on the global. Focusing on one detail after the other, he creates an artistic whole, with perfection in each detail with no prior plan on how to achieve the end (Mayers, Baron-Cohen, & Wheelwright, 2004). This is probably a completely opposite strategy to the natural and common for a TD person. In recent accounts of the theory it was stressed that the detailed- focused style is a processing bias rather than a processing

deficit. The inclination to local processing can be overcome if the individual is specifically instructed to process globally (Happé & Frith, 2006). Weak central coherence may play a role in enhanced perception and hyperreactivity and sensory interests as follows: Weak central coherence > enhanced attention to disparate stimuli > strong sensory interests and interest in sensory details.

Common diagnostic assessments of ASC

This review of diagnostic instruments is not intended to be comprehensive. Those most commonly used in clinical assessments and gold standard instruments are included. For a more comprehensive survey see Charman and Gotham (2013).

Diagnostic parent/other informant interviews

Examples of parent (or other informant) diagnostic interviews that are used with children but also can be used when assessing adults are the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter & Le Couteur, 1994), and the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al. 2002.) ADI-R and DISCO can be used for all levels of ability. ADI-R is the gold standard instrument. The Asperger Syndrome (and high functioning autism) Diagnostic Interview (ASDI; Gillberg et al. 2001) is a briefer instrument, specifically developed for high functioning individuals. It can be difficult to use the detailed ADI-R and DISCO interview in retrospect with parents or other informants because of the time that has elapsed since childhood. DISCO covers more sensory issues than both ADI-R and ASDI.

Diagnostic observational instruments

For observational diagnostic assessments the gold standard instrument is the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 2011). ADOS is designed for all ages, ability and severity levels and there is a module (4) specifically designed for adults. There is only one sensory item in ADOS covering unusual sensory interest in play, material or person exemplified by e.g. sniffing, touching, feeling of texture, licking, mouthing or biting, repetition of certain sounds, or unusual or prolonged visual examination. The sensory symptoms in the item are clearly not adapted for high functioning adults, and the item has the same wording in all modules.

Screening for autistic-like traits or for ASC with self-report scales

Self-report instruments specifically designed for and commonly used with adults are the Autism-Spectrum Quotient (AQ; Baron-Cohen et al. 2001) and the Ritvo Autism and Asperger Diagnostic Scale-Revised (RAADS-R; Ritvo et al., 2011). AQ is a screening tool for identification of autistic-like traits and not a diagnostic tool. It comprises five subscales: social skill, attention switching, attention to detail, communication and imagination. RAADS is a self-report scale based upon the diagnostic criteria for ASC in DSM-IV-TR (APA, 2000) and the ICD-10 (WHO, 1992). It was designed to be an adjunct diagnostic tool. RAADS-R has four subscales: social relatedness, language, circumscribed interests and sensory-motor. RAADS covers a range of sensory issues while the AQ only cover enhanced perception of visual and auditory stimuli.

Introduction to sensory perceptual issues in ASC

Since Kanner sensory perceptual features have continuously been part of the descriptions of ASC and there are also theories of autism involving sensory perceptual issues (e.g. Ornitz & Ritvo, 1968; Mottron, Dawson, Soulières, Hubert & Burack, 2006). There is no theoretical model that fully explains the sensory phenomena observed in ASC (Gerrard & Rugg, 2009; Rogers & Ozonoff, 2005). Sensations connect us with the world and with ourselves. Sensations are broadly defined as the "conscious or subconscious awareness of external or internal stimuli" and a corresponding broad definition of perception is "conscious awareness and the interpretation of the meaning of sensations" (Tortora & Grabowski, 2000, p. 485). Hence perception moves beyond sensation and involves preconceptions and feelings in the interpretation of sensations. Each type of sensation such as touch, pain or sound belong to a distinct sensory modality, a given sensory neuron carries information from a specific modality (Tortura & Grabowski, 2000).

Sensations and perception

There is no sharp line between sensations and perceptions. They are part of a process that starts with stimuli in the environment and ends with interpreted perceptions that can be stored in the memory and used in thought processes. Stimuli, e.g. light or soundwaves reach the sensory organs and are transformed in specialized sensory receptors that transduce the energy into a graded potential. When a graded potential reaches threshold, nerve impulses are triggered that propagate to the central nerv-

ous system (CNS). The CNS receives and integrates the sensory nerve impulses in steps involving several areas of the brain and mental representations are formed. Perception is influenced by cognitive and emotional factors such as prior knowledge, expectations and goals. This is what is known as top-down perception. A contrasting process is bottom-up perception, i.e. the information contained in the neural signals from the receptors to the brain. Bottom-up perception involves the combination of simple sensory features into more complex shapes until final integration of a percept (Rooks & Willson, 2007).

Sensory processing and developmental psychology

Human sensory systems are immature at birth and become increasingly refined during development as multisensory perceptual capacity broadens. Complex abilities such as facilitation of speech perception in noise have been reported to be immature throughout childhood (Burr & Gori, 2012). Recent research indicates that there are also narrowing processes. Young infants are broadly perceptually tuned and tend to respond indiscriminately to all perceptual inputs (Lewkowicz, 2014). The narrowing processes starts as a consequence of experience. The effect of these maturing processes is an increase in the child's perceptual sensitivity and responsiveness to stimuli that represent their typical ecological setting with a corresponding decrease in relation to other stimuli.

Development of joint attention has been linked to the time when the infant can point, use gestures to refer to objects, and has the intention to communicate. The infant then discovers that the focus of attention can be shared. The infant perceives his or her own attentional focus and that of the other person and that these can be similar or different. The development of joint attention enables the child to seek affective information from the "other" to evaluate the shared focus of interest (social referencing), which is developed between ten and twelve months (Klin, Schultz & Cohen, 2000). A non-egocentric understanding of perception is crucial for perspective taking and is developed around three years of age. At around seven years of age children begin to understand that people can interpret ambiguous stimuli in different ways (Gopnik, Capps & Meltzoff, 2000).

There is no comprehensive developmentally based theory of perception in autism. Research is somewhat fragmentary, as is also the case for the entire dimension of restricted, repetitive, and stereotyped behaviors (Leekam, Prior & Uljarevic, 2011). This is surprising in the context of autism being per definition a developmental condition. Leekam et al argue

a need for a broader focus that brings together disparate areas of research on the second dimension of ASC (table 1).

Sensory processing and cognition

There is an ongoing discussion in ASC research on whether phenomena like enhanced perception have a sensory perceptual base (bottom up) as proposed by Mottron et al. (2006) or higher level cognitive explanation like weak central coherence (Happé & Frith, 2006). The sensory perceptual differences in ASC are probably too complex and heterogeneous among individuals to be explained by one or the other of these models. A model for human perception where initial bottom up perception (sensory features) is followed by top- down (based on expectancy and goal set) may be needed to solve this disagreement (Theeuwes, 2010).

Sensory issues and intellectual level

Few studies on atypical sensory reactivity have information about intellectual level but there is some evidence of sensory issues at all levels of intellectual ability. In a study by Leekam et al. (2007), sensory symptoms did not vary with IQ and sensory issues were also found in the highest functioning adults. Leekam et al. (2007) concluded that sensory symptoms are pervasive, multimodal and persistent across intellectual ability in children and adults with autism.

Sensory issues, age and gender

Study results on age differences are inconsistent with some indications of hyporeactivity decreasing with age (Kern et al., 2007) and of indication of increased hyperreactivity with age (Liss, Saulnier, Fein & Kinsbourne, 2006). These results should probably be interpreted with caution. For instance hyperreactivity may be increasingly evident as the child matures and has more opportunities to express its manifestations. The overall picture is that sensory symptoms are still prominent in adults. In the study by Leekam et al. (2007), sensory symptoms were shown to persist into adulthood. In a longitudinal, prospective, community-based study of adults who had received a diagnosis of autism in childhood, a majority of the study group (93%) still had impairing sensory symptoms in adulthood (Billstedt, Gillberg & Gillberg, 2007).

It is hard to find information on gender differences in atypical sensory reactivity. Even large studies e.g. Tomcheck et al. (2007) or Leekam et al. (2007) do not account for gender differences.

Atypical sensory reactivity from the perspective of the individual with ASC

Patterns of sensory processing across modalities are commonly reported as hyper- and hyporeactivity and unusual sensory interests, although there are many other sensory and perceptual disturbances in self-reports and parent-reports (see Bogdashina, 2003 for a review). Hyperreactivity refers to strong reactions to sensory stimuli. There are many examples in the literature. For example Temple Grandin (2005), a Professor of Animal Science and an author with ASC, describes her touch sensitivity: "Still, when she hugged me, I was totally engulfed and I panicked. It was like being suffocated by a mountain of marshmallows. I withdrew because her abundant affection overwhelmed my nervous system" (p. 25-26). Hyporeactivity refers to a seeming lack of reaction or a diminished reaction to sensory stimuli. Examples offered in DSM-5 are not reacting to pain or temperature. Tomas McKean (1994), author and advocate for people on the autism spectrum, wrote "What is hunger? I am not sure I know, I rarely, if ever, feel a need to eat anything" (p. 42). Fascination with lights or movements is examples of unusual sensory interests in DSM-5. Wendy Lawson, (2003) researcher, psychologist, and author with ASC, wrote about her affection to color: "Color and shiny surfaces are just examples of mediums that connect me to life and to feeling" (p. 2).

Sensory perceptual theories of autism

A definition of autism where sensory perceptual disturbances played an important role was proposed by Ornitz & Ritvo (1968). Their definition of autism included clusters of symptoms in five areas; perceptual integration, motility patterns, capacity to relate, language and developmental rate. In the model disturbances of perception was thought to underlie most of the other clusters of symptoms. More precisely they proposed that inability to maintain constancy of perception was the underlying mechanism. Environmental stimuli are either not adequately modulated or are unevenly amplified resulting in overload or underload of the central nervous system. They described heightened awareness of sensory stimuli, heightened sensitivity and irritability, non-responsiveness and motor behaviours associated with sensory input. Aberrations were described in auditory, visual, tactile, gustatory, olfactory, proprioceptive and vestibular senses.

A theory of enhanced perceptual functioning in autism

The theory of enhanced perceptual functioning in autism (EPF; Mottron et al., 2006) proposed that lower order perceptual functions (detection, dis-

crimination, and categorization of stimuli) are enhanced. The default setting of perception in ASC is more locally oriented as compared to the mandatory higher-order processing in typical individuals. For TD persons higher-order processing is mandatory, even when it is detrimental to performance, whereas individuals with autism are able to regulate perceptual versus higher-order control more flexibly. Highly specialized neural networks predispose the locally oriented and enhanced perceptual functioning. The EPF model emphasizes perceptual processes, rather than social or higher order cognitive processes in explaining cognitive and behavioural patterns in autism and the autistic phenotype. Circumscribed interests and special abilities in ASC are considered to be adaptions to the enhanced perceptual capacity, special abilities are presumed to be underpinned by perceptual expertise, and circumscribed interests can be viewed as interest in certain classes of stimuli like tones, words, patterns, numbers etc. The default exactness of this information processing can be illustrated by the artist Peter Myer's (Myers et al., 2004) answer to the question "Where do you live?" "What information are you after? Do you want to know which country I live in, or which county I live in, or which city I live in, or which neighbourhood, or which street, or which house? Or maybe you are asking which room in the house" (p. 13).

Models of sensory processing

Olga Bogdashina outlined a comprehensive model of the sensory perceptual world in autism (Bogdashina, 2003) that comprises many aspects of differing sensibility, perception and cognition. The DSM-criteria of hyperor hypo-reactivity and sensory interests is only one aspect of the differences described. The overarching concept in the model is gestalt perception (inability to distinguish fore- and background; ibid.) resulting in different sensory experiences, perceptual styles and compensation strategies. Examples of sensory experiences are fragmented perception, distorted perception, delayed processing, hyper- and hyposensitivity, fascination etc.

The Interdisciplinary Council on Developmental and Learning Disorders (ICDL) has developed a classification for Sensory Processing Disorder (SPD). According to the ICDL classification there are three sensory processing disorders: (a) Sensory modulation disorder characterized by an inability to grade and control the intensity of sensory stimuli as well as the behavioural response, (b) sensory discrimination disorder represents a difficulty to interpret and recognize specific qualities of stimuli, and (c) sensory based motor disorder refers to difficulty with body movement and

stability (Greenspan & Wieder, 2008, p. 11). SPD is not in the DSM-5 manual, but is used by some occupational therapists, who diagnose SPD as a "stand alone" diagnosis.

Dunn (1997) developed a theoretic generic (applicable to all people) model for sensory processing, i.e. not specific to ASC. Low sensory thresholds are supposed to interact with behavioral responses and cause sensory avoidance or sensory sensitivity. Similarly, high sensory thresholds interact with behavioural responses and cause low registration or sensation seeking. Two scales for assessment based on this model were developed, the Sensory Profile (Dunn, 1999) and the Adolescent/Adult Sensory Profile (A/ASP; Brown & Dunn, 2002).

The models resemble each other in their conceptualization of the sensory process of hyper- hypo- and strong sensory interest. Bogdashina's model is broader and has an empirical base in observations of behaviours and self-reports from people with ASC. The ICDL and Dunn's model have a theoretical base and ICDL is an impairment model based on deviations from what is considered normal. Every day function is also in focus. Bogdashina's model placed the focus on the experience and behaviour dimensions of people with autism and not normality. Moreover ICDL is directed towards dysfunction whereas Bogdashina also addresses enhanced abilities based on sensory issues, namely beneficial aspects of having atypical sensations and perceptions.

Overview of the sensory reactivity research field Experimental research

There is an interesting discrepancy between parent- and self-report studies and psychophysical and neurophysiological research. Parent- and self-reports consistently describe a high degree of atypical sensory reactivity, while results from experimental research are inconsistent. I will discuss this briefly. A comprehensive account of the underlying neurobiological and neurophysiological explanations for sensory differences is beyond the scope of this thesis. For a review of neurophysiological research on the sensory channels most often affected in ASC: auditory, visual and tactile stimuli, see Marco et al., (2011).

There is some support for measurable atypical sensory reactivity. Examples are deficits in speech perception in noise (children with ASC; Alcantara, Weisblatt, Moore, & Bolton, 2004), and deficits in processing speech in quiet as well as background noise conditions (children with ASC; Russo, Zecker, Trommer, Chen, & Kraus, 2009). Heightened olfac-

tion has been found in adult males with ASC (Ashwin, Chapman, Howells, Rhydderch, Walker, & Baron-Cohen, 2014). Hyperreactivity to tactile stimulation in some frequencies and experimental conditions have been reported (Blakemore, Tavassoli, Calò, Thomas, Catmur, Frith, & Haggard, 2006; Cascio, McGlone, Folger, Tannan, Baranek, Pelphrey, & Essick, 2008). In contrast O'Riordan & Passetti (2006) did find superior auditory but not enhanced tactile discrimination in ASC relative to controls. Bölte et al. (2012) did not find evidence of enhanced visual perception. These differing results may be due to a high degree of heterogeneity with atypical reactivity in some areas and average perception in other areas (Cascio et al. 2008). In addition the affected areas of atypical reactivity seem to be highly individual.

Neurophysiological underpinnings of sensory processing are often measured using event-related potentials (ERPs) with electroencephalography (EEG) and magnetoencephalography (MEG). Stimuli are presented, and brain responses are registered. Examples are: a) Sensory thresholds measuring the lowest threshold for perceiving a stimulus, b) Assessments of the ability to discriminate between stimuli, c) Assessments of the brain's capacity to regulate its sensitivity to stimuli (sensory gating), and d) The capacity to integrate information from multiple modalities (Baranek et al. 2014). There is also experimental research on differences in physiological activation in response to a sensory stimuli measured through heart rate, blood pressure, electrodermal activity and measurement of cortisol (Lydon, Healy, Reed, Mulhern, Hughes, Goodwin, 2015).

Some of the discrepancies in experimental research may be due to variation in ages, severity levels of ASC, possible subtypes of ASC, and methodological differences. It is also important to consider that sensations can be measured objectively, e.g. through establishing thresholds or discrimination of sensations, but perception (interpreted sensations) is individual and subjective. Research has not yet solved the problem of the discrepancy between objective measurements and subjective experience.

Qualitative research on sensory reactivity with adults diagnosed with ASC

Autobiographies with accounts of sensory perceptual issues by people with ASC are rather common and are sometimes cited in research, but we found only a handful of qualitative research studies on sensory and perceptual issues in adults with ASC (Chamak, Bonniau, Jaunay, & Cohen, 2008; Jones, Quigney, & Huws, 2003; Robledo, Donnellan, & Strandt-Conroy, 2012; Smith & Sharp, 2013). Qualitative studies share major

themes like hyperreactivity and sensory overload causing distress. Sensations are described as a source of both pleasure and discomfort and sensory reactions in general have a stronger and sometimes disruptive impact, compared to the way they are experienced by people without autism. This is obvious in all qualitative studies. The need for strategies to compensate for atypical sensory reactivity is also regularly described in qualitative research.

Instruments for measuring sensory reactivity

Instruments mainly used for measuring sensory reactivity in research are presented in table 2. In psychiatric clinical work with adult patients with ASC their use seems to be limited. The scales are solely based on observations (research, clinical, and parent report) which entail the risk of missing unobservable information that can only be obtained through communication with the individuals with these experiences. In addition there is a child perspective, even the adolescent/adult sensory profile, is constructed from the sensory profile for children. The behavioural manifestations of sensory reactivity are not the same in high functioning adults as in children with or without ASC. There is a perspective in the SP on deviations from what is considered normal behaviour, but the distinction between sensory issues and problematic behaviour in general is not totally clear. The SP and A/ASP are based on a theoretical model, intended to be applicable to the general public (Dunn, 1997).

Table 2 Sensory so	scales currently used in research		
Reference	Scales and Classifications	Conceptual frame- work	Subscale content
Dunn (1999) Brown & Dunn (2002)	Sensory Profile (SP; Dunn 1999) Parent report 125 items 3-11 years Adolescent Adult Sensory Profile (A/ASP) self-report 60 items, 11 years through older age	Generic, theory based Neurological thresholds interact with behavioural strategies	Sensitivity (low threshold, passive response) Avoidance (low threshold active response) Low registration (high threshold passive response) Seeking (high threshold active response)
Talay-Ognan & Wood (2000)	Sensory Sensitivity Questionnaire (SSQ) parent report 54 items 4-14 years	Autism specific, based on prior assessments	Hypersensitivity Hyposensitivity
Baranek et al. (2006)	Sensory Experiences Questionnaire (SEQ) parent report, 21 items 5-80 months	Autism specific based on prior theory and research	Hypersensitivity Hyposensitivity Social non-social context
Baranek (2009 un- published) referred to in Ausderau et al. 2013	Sensory Experiences Questionnaire Version 3 (SEQ-3.0) 105 items	Autism specific based on prior theory and research	Hyperresponsiveness (HYPER) Hyporesonsiveness (HYPO) Sensory interests, repetitions, seeking (SIRS) Enhanced perception (EP) Social/non-social context
Roberson and Simmons (2013)	Glasgow Sensory Questionnaire (GSQ) 42 items Adults	Prior assessments (Baranek, 2006: Bogdashina 2003) and parent report (Robertson & Sim- mons 2008)	Hypersensitivity Hyposensitivity
Tavassoli et al. (2014)	Sensory Perception Quotient (SPQ) 35 items short version Adults	Basic sensory sensitivity (no social or affective aspects)	Hypersensitivity

Rationale for this thesis

There is a large amount of sensory research based on parent-report measures (e.g. Baranek et al., 2006; Ben-Sasson et al., 2009; Tomcheck and Dunn, 2007) but studies of adults that use self-reporting are scarce. A few studies involved both children and adults (Leekam; 2007; Kern et al., 2006). One study with few participants involved exclusively adults using the A/ASP (Crane, Goddard, & Pring, 2009).

Overall, the research in the field of autism has concentrated on children and on social deficits. Research involving adults is still uncommon. The study of sensory and motor issues in autism is a relatively new frontier for research in ASC and one that arouses great interest among people with own diagnoses and among self-advocates. Recently some researchers have conveyed their emerging awareness that people may be struggling with sensory and motor difficulties that are not immediately evident to an outsider (Donnellan, Hill, Leary, 2013; Robledo et al., 2012). We are advised, not to take for granted, that our experience of people with ASC is the same as their own. Non-autistic people often interpret symptoms as meaningless or as signs that the person with ASC is not interested in relating or communicating. Donnellan et al. (2013) argue that the interpretations of "autistic behavior" that the non-autistic world makes are socially constructed. This may not be compatible with the lived experiences of people with ASC. In other words, social interpretations of other people's behaviour are hard wired in the brains of TDs, but persons with ASC may experience their reality very differently. The social focus may mean that sensory and movement differences are unrecognized. In our studies we address these issues and aim to do so by listening to the experiences and views of people with ASC.

Aims

The overall general aims of the thesis were to capture the first hand experiences and perspectives on sensory reactivity and translate them into a self-rating scale.

The specific aim of each study was as follows:

Study I: To explore and describe hyper- and hyposensitivity in the context of verbal expressions of high-functioning persons with ASC.

Study II: To explore and describe personal sensory experiences of adults with ASC.

Study III: To develop and pilot test a self-report questionnaire for sensory reactivity based on first-hand descriptions from the target group of adults with high functioning ASC.

Study IV: To identify subgroups of people with similar sensory features in an ASC sample and in a population sample separately.

METHODS

Here the general methodology and design of the research project is described and data collections and methods of analyses are reviewed. Specific details of the analyses are presented in the separate studies.

General design of the thesis

The general design is presented in figure 1. We used a sequential mixed-methods design (Mayring, 2007) with two qualitative studies and two quantitative studies. We conducted the qualitative studies of autobiographies (I) and interview (II) to inform the development of a questionnaire to measure atypical sensory reactivity in adults with ASC. Study III was an instrument validation study in a clinical psychiatric, habilitation and a general population setting, with a cross-sectional design. In study IV cluster analysis was applied in a clinical psychiatric and a general population setting, with a cross sectional design.

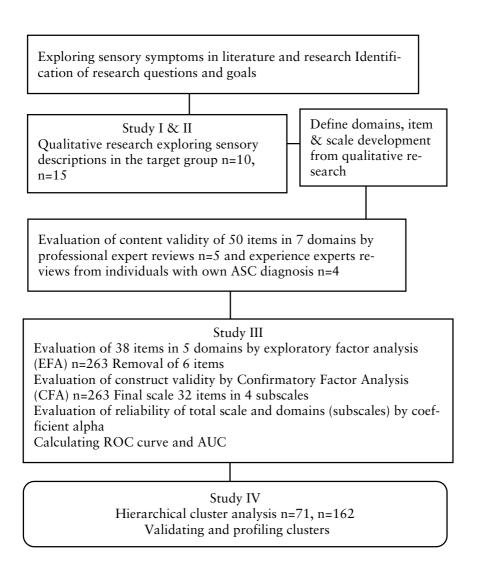


Figure 1. Overview of the thesis and studies I-IV

The qualitative studies

We used qualitative content analysis (CA) in both study I and II. CA is a method for making valid inferences from texts by classification of meaning into categories that have been created from the text content (Krippendorff, 2004; Weber, 1990). The focus of the analytic work in CA can be at any place on the spectrum of manifest to latent content, and approaches can be inductive (study II), deductive, or inductive/deductive, stepwise building a theoretical frame. In study 1 a directed analysis was conducted (Hsieh & Shannon, 2005; Mayring, 2000) which started from a simple model of hyper- and hyporeactivity as initial concepts (deductive approach) that was further inductively developed from the text material. In study II an inductive approach was applied (Burnard 1991).

Sources and participants in the qualitative studies

Published autobiographies by ten authors with an ASC diagnosis from different parts of the world were sources for a qualitative study of documents (study I). Five of the autobiographies were by women and five by men.

For the interviews (study II) 15 participants were recruited from one county in Sweden. Inclusion criteria were a minimum age of 18 and a formal diagnosis of ASC. Because of the interview requirements of oral fluency and spoken language comprehension, we instructed the personnel who recruited the participants to identify individuals without intellectual disabilities, and with an adequate command of the Swedish language. The inclusion criteria were related to the aim of the study, which was to gain rich verbal descriptions of sensory reactions. The participants had received a clinical diagnosis of Asperger disorder or Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS) according to DSM-IV-TR (APA, 2000) and to the ICD-10 (WHO, 1992). Eight women and seven men agreed to participate. Their ASC diagnoses were registered in medical records. The information about comorbid diagnoses was obtained from the participants themselves, and comorbidity was not checked against medical records. Eleven of the participants were diagnosed by multidisciplinary psychiatric teams specializing in the assessment of childhood onset neuropsychiatric conditions, and four of the participants had been diagnosed by a psychologist in cooperation with a psychiatrist.

Procedures in the qualitative studies

We found references to autobiographies (study I) on four Internet Web sites: The Autism and Asperger Association, National Autistic Society, Autism Society of America, and Neurodiversity. We read seventeen works published in Swedish or English, and selected ten autobiographies using Scott's (1990) quality criteria for assessing documents for research purposes (a) authenticity, (b) credibility, (c) representativeness, and (d) meaning. We chose ten authors who are well known as representatives of persons with ASC. We chose life stories rather than works on specific topics, and if there were several life narratives written by the same author, we chose the first. All the autobiographies were written after a formal diagnosis of ASC had been received. In addition, we aimed for a gender balance and variation in age at diagnosis.

The staff in two psychiatric outpatient teams and one habilitation team in Sweden recruited the participants in the interviews (study II). The staff had access to medical records and diagnoses of the participants, and they contacted eligible participants and provided them with a written explanation of the study. The recruitment personnel organized contact between those who agreed to participate and the first author who conducted the interviews. The time and place of each interview was scheduled according to the participant's preferences, and before starting the interviews the participants again received information about the study and gave written consent. The semi-structured interviews were audio taped and transcribed verbatim.

We developed the interview guide on the basis of study I and adapted it to the communication needs inherent in ASC. Vague questions were avoided due the need for clear and precise communication. The questions were concrete involving one sense at a time but open-ended as they were intended to prompt descriptions of how stimuli of different kinds were perceived. The purpose was to capture the participant's unique experience. After completion of a specific sensory area, participants were asked if they had additional information they wished to add on the topic. All topics planned beforehand were discussed in all interviews. The interviews lasted between 30 and 90 minutes and I conducted all interviews myself in the period March 2009 until August 2010. The participants chose where the interviews took place: at their clinic (twelve), in their homes (one), at their workplace (one), at the first author's work place (one).

Qualitative data analysis

In the study of autobiographies (study I) all text material first was read trough. We used an initial coding scheme of hyper- and hyporeactivity broadly defined as over- and underreactions to stimuli to select all the relevant autobiographical text passages. The coding agenda for hyper- and hyporeactivity was developed using the different forms of sensory reactions (visual, auditory, touch, pressure, smell, taste, balance (vestibular stimuli), warm cold (thermal stimuli), pain, proprioception (stimuli from muscles and joints) and interoception (stimuli originating inside body) inductively derived from the text and was revised in an iterative process. Finally we worked through the text assigning codes according to the final coding agenda to the sensory reactivity statements (table 3). We checked for reliability with percentage agreement with a second coder who coded the text passages using the final coding agenda for hyper- and hyporeactivity and sensory modalities. The percentage of agreement between coders was 0.88 for hyper codes and 0.76 for hypocodes. Recommendations for acceptable intercoder reliability vary. Cutoff figures between 0.70 and 0.80 have been proposed (Neuendorf, 2002).

Table 3 Data analysis in Study I

Table 5 Data	analysis in Study i
Method	Directed content analysis, adapted from (Mayring 2000; Hsieh & Shannon, 2005)
Application	A method for conceptual extension and validation of a theory
Step 1	All text was read through in a process of immersion
Step 2	An initial coding scheme with hyper- and hyporeactivity as key concepts with a preliminary broad definition of over- and underreactions to stimuli was used
Step 3	All text was read again and text about sensory reactivity was highlighted and coding scheme was developed with the different sensory reactions included in the scheme in an iterative process
Step 4	Final revision of coding scheme
Step 5	Return to texts and selected text passages were coded with the final coding scheme
Step 6	Reliability check of percent agreement with an independent coder who coded all selected passages against the final coding scheme
Step 7	Interpretation of the results
Step 8	A quantitative step calculation of frequencies

In the inductive CA (study II) categories were formulated step by step inductively from the text in an approach adapted from Burnard (1991; table 4).

Table	1	Data	anal	veis	in	study	П
Table	4	Data	anai	V515	111	Stuuv	н

Method	Inductive content analysis (adapted from Burnard (1991)
Application	A method of analysing interview transcripts in qualitative research
Step 1	Verbatim transcripts of interviews were read through in a process of immersion
Step 2	Shortened text passages were assigned a code, that condensed the content Thereafter similar codes were grouped together under higher order codes (subcategories) in a separate process for each interview
Step 3	A list of codes and subcategories was developed and reworked in an iterative process
Step 4	A college was invited to go through the codes and subcategories in two of the interviews and adjustments were made.
Step 5	Each transcripts was coded according to the agreed list and higher order categories were proposed
Step 6	Transcripts were read again with the agreed list, to establish that the interview content was covered
Step 7	The coded sections from each interview were selected and sections with same coding were gathered together. The process no longer involved each interview, all material was viewed together. Similar codes, and subcategories were organized under higher order categories
Step 8	The final categorization of the material was reviewed by the fourth author
Step 9	A quantitative step counting numbers of statements and number of interviews with statements

Development of the instrument - Sensory Reactivity in Autism Spectrum (SR-AS)

Items were developed according to the steps recommended by De Villis, (2003).

- 1. An item pool was generated from the descriptions made by people with ASC diagnoses in study I and II.
- 2. Professional experts and individuals who themselves had ASC diagnoses reviewed the items. A content validity index based on professional experts review and comments from the ASC reviewers was used. In the process 34 items were rephrased and the number of items reduced from 55 to 50. One item on strong reactions to stimuli that do not seem to bother other people was judged to be too vague. One item on not reacting to forceful movement was judged unclear and not relevant. Two items on strong stimuli preferences (music, sounds, and forceful movements) were considered too vague and not relevant. These items were removed. Two sensory motor items, on problems to adapt force output in different activities were collapsed to one item.

- 3. The response format was determined using a 4-point Likert scale ranging from totally disagree (0) = No atypical sensory reactivity, partly disagree (1) = Quite low atypical sensory reactivity, partly agree (2) = Quite high atypical sensory reactivity, and totally agree (3) =Very high atypical sensory reactivity. Background questions about demographics and the possibility to make individual comments were included and for respondents with ASC a question about comorbid diagnoses was added.
- 4. The instrument was administered to an ASC sample and a sample from the general population.

The quantitative studies

Procedures in quantitative studies

Adults with ASC were invited to participate (III and IV) by psychiatric and habilitation personnel in two counties who also provided oral information about the criteria for inclusion and the design of the study. Each participant from the ASC group was approached and checked for eligibility by a staff member who knew the individual. The 71 ASC participants were recruited from April 2012 to May 2014. Those interested in participating received an information letter with a more detailed explanation. All patients were informed that their participation was voluntary and anonymous. Written consent was not sought so that participants could be anonymous. Those who gave oral consent were asked to complete the questionnaire, place it in a prepaid envelope and seal it either at the clinic or later.

Respondents from the general population were selected at random from the Swedish national address register (Statens personadressregister (SPAR, 2011). SPAR includes all individuals who are registered as residents in Sweden. We selected a sample of 500 respondents from the same two counties as the clinical respondents and stratified the sample by age. The stratification was based on the age distribution of individuals with ASC diagnoses who were in contact with the clinics in one of the counties during 2011 in order to facilitate comparison between samples. An information letter explained the rationale for the study and stated that participation was voluntary and anonymous. We mailed the information letter, the questionnaire, and a prepaid reply envelope to the respondents in January 2013 and sent a reminder after three weeks. Fifteen addresses were incorrect and thus the final initial sample comprised 485 persons. Ninety-

eight of the participants responded without being reminded and 66 after receiving the reminder, the total response rate was 33.8 %. Two questionnaires were excluded due to missing data.

Participants in quantitative studies

The majority of the ASC sample were outpatients (n=61) and a minority inpatients (n=8, missing information in 2 cases). Their ages were 18 or older, and all had a clinical diagnosis of autism, Asperger disorder or PDD-NOS registered in medical records according to ICD-10. The most frequently self-reported comorbid diagnoses in the ASC sample were depressive disorders, anxiety disorders and ADHD/ADD from around 30 to 40% (more than one comorbid disorder could be reported). Only 11% did not report any comorbid diagnoses. Socio-demographic data are presented in table 5.

Table 5 Socio-demographic characteristics of participants in the quantitative studies (n=233)

Characteristics	ASC sample n=71 n(percentage)	Population sample n=162 n/percentage	Р
Gender			0.60
Women	41(57.8)	93(57.4)	
Men	26(36.6)	69(42.6)	
Information missing	4(5.6)		
Age groups			0.65
18-24	22(31.0)	44(27.1)	
25-44	36(50.7)	80(49.4)	
45-65	13(18.3)	38(23.5)	
Highest education			<0.001*
Secondary school	21(29.6)	11(6.8)	
Upper-secondary school	37(52.1)	95(58.6)	
Tertiary education	11(15.5)	56(36.6)	
Information missing	2(2.8)		
Family situation			<0.001
Married/cohabiting	19(27)	98(60.5)	
Single with children	8(11)	7(4.3)	
Single	39(55.0)	55(34.0)	
Information	5(7.0)	2(1.2)	
Current occupation			<0.001
Working or studying	20(28.2)	141(87.0)	
Currently not working or studying	48(67.6)	17(10.5)	
Information missing	3(4.2)	4(2.5)	

^{*}Pearson Chi-square test, all other Fisher's exact test

Quantitative data analyses

Before psychometric evaluation of the instrument the items in two dimensions based on the categories from qualitative study II, Regulation of attention and Managing consequences of sensory reactivity were omitted as not being direct measures of sensory reactivity.

Analyses conducted in the quantitative studies are summarized below, SPSS version 22 was used for all data analyses. The distributions of data in respective sample was explored and tested with the Kolmogorov-Smirnov test. We conducted exploratory factor analysis (EFA) using the Principal Axis Factoring extraction (Costello & Osborne, 2005; Hair, Anderson, Tatham, & Black, 1995) and oblique rotation (promax) on the combined samples. Items in five presupposed domains were tested in the EFA: High Awareness/Hyperreactivity (twelve items; e.g. "I often feel great discomfort when other people touch me"); Low Awareness/Hyporeactivity: (eleven items; e.g. "I often feel no pain at times when other people think I should"); Sensory overload (five items; e.g. "Constantly smelling a certain smell or hearing a certain sound make me feel exhausted"); Strong sensory interests (four items; e.g. "When I look at certain patterns or colours or hear certain sounds/tones I often find them extremely fascinating"); Sensory/motor (six items; e.g. "In everyday situations I often feel clumsy because I drop things, for example, or spill a lot"). Six items were removed after EFA. Three general sensory overload items (being easily exhausted in places where there are many people who are moving around, participating in large groups of people, and being exhausted by environments offering many impressions) as well as one hypo-reactivity item (only grasping certain words in the speech of others) were removed due to overly high correlations (> 0.80) suggesting redundancy. Two sensory/motor items (strong reactions to movements and problems to adapt the force exerted in activities) were removed due to low loadings and cross loadings. The latent structure of the 32 remaining items was tested with confirmatory factor analysis (CFA) using AMOS 22 (Byrne, 2010). Different factor structures were evaluated and compared. The method of estimation was maximum likelihood. CFA using structural equation modelling (SEM) can be used to evaluate single or competing models. In the present study III, it was determined which of several models best fitted the data. The overall model fit was evaluated by chi-square test and df-ratio. The incremental fit index presented was the Comparative Fit Index (CFI). Absolute fit indices presented were Root Mean-Square Error of Approximation (RMSEA) and Standardized Root Mean-Square Residual (SRMR).

Reliability analysis in the form of internal consistency (Cronbach's alpha coefficient) was conducted on the 32 item scale and subscales (factors). A coefficient of 0.70 or higher was considered satisfactory (Nunally & Bernstein, 1994).

The discriminative power of the SR-AS i.e. discrimination between participants with an ASC diagnosis from the population sample was conducted using Receiver Operating Characteristic (ROC) curve analysis and area under the curve (AUC). The null hypothesis (no discriminative power) is AUC = 0.5.

Due to the non-normal distribution of data in the population sample we used Mann Whitney U test for comparison of the CFA sensory factors in the ASC group and the population sample.

Hierarchical agglomerative cluster analysis (Hair, Anderson, Tatham, & Black 1995) was conducted to identify subgroups with similar sensory features in the ASC group and in the population sample separately. Clustering was determined by Ward's method and squared Euclidean distance was used as similarity measure. The stability of the hierarchical Ward's cluster solution for the respective samples was examined using a non-hierarchical k-means cluster analysis with the number of clusters specified in advance based on the hierarchical analysis solutions.

We gave descriptive statistics for clusters (numbers, means and standard deviations). ANOVA with post-hoc tests were conducted in the ASC group to assess differences between clusters on the four subscales. Effect sizes for differences in F-statistics were calculated as eta squared. The Mann Whitney U test was used to assess differences between clusters in the population sample because of the non-normal distribution of scores. The alpha level for all statistic tests was set at p < .05.

For assessments of differences in demographic characteristics between samples we used the chi-square test and Fisher's exact test where appropriate. Assessments of associations between clusters and sociodemographic variables were assessed by the chi-square test and Fisher's exact test.

Ethical considerations

We developed the methods and procedures for the studies in compliance with the ethical principles of the Helsinki Declaration (World Medical Association, 2013). Participants in study II were informed orally and in writing that participation was voluntary and they had the right to withdraw at any time without providing an explanation. Confidentiality was assured and informed consent was obtained. The interviews were audi-

otaped and coded (study II) and the recorded interviews were stored safely without name or birth registration number. A letter with information about the background and purpose of the study, and stating that participation was voluntary and anonymous (study III, IV) was provided and the questionnaires were filled out anonymously. There was no dependent relationship between the participants and the researchers (study I-IV). All studies except the document study (I) were approved by the Regional Ethical Review Board in Uppsala. Ethical approval was not needed for study I since it was a documentary study. An issue in study I was the use of copyright-protected work. We judged our use of circumscribed quotes in the texts to be in compliance with guidelines for the right to quote for research purposes and therefore permission to quote from the autobiographies was not sought. Another ethical concern was to fully respect the intended meaning conveyed by autobiography writers as we understood it. A fundamental ethical consideration made when conducting these studies involved adherence to the individual experience perspective as well as fidelity to this standpoint through all the studies in the thesis. Much of the research in the area of autism is conducted from other perspectives e.g. the perspective of researchers, clinicians or parents.

RESULTS

The results from the studies I-IV are summarized below. Qualitative and quantitative results are presented in separate sections.

Qualitative study results

Our aims in the qualitative studies were to describe and to explore sensory reactivity in ASC from the first-person perspective and capture the variations and diversity of the phenomena. The nature of the hyper- and hyporeactive responses was described in detail (study I; figure 2). The autobiographies revealed the wide variation in atypical sensory reactions. These included reactivity to visual and auditory stimuli, touch and pressure, smell taste, vestibular (balance), thermal (warm cold), and pain stimuli as well as proprioception (stimuli from muscles and joints) and interoception stimuli (stimuli originating inside body).

Category Frequency Description	Hypersensitivity 77 quotations 10/10 autobiographies Strong positive or negative reactions, discomfort, pain, absorption, fascination. Heightened detection and apprehension of stimuli sometimes in combination with over focused or unselective attention		Hyposensitivity 54 9/10 autobiographi No or indistinct reg stimuli, less discrin recognition of stimu cravings for specific a stabilizing effect	es istration of nination and uli and strong
Duration	Persistent hyper	Episodic hyper	Persistent hypo	Episodic hypo
Description	Long-term states, exter- nal stimuli	Temporary states, external stimuli, unex- plained shifts to hypersensi- tivity	Long-term states, mostly body and internal stimuli	Temporary states, external stimuli. Shifts are caused by absorption, inner focus or overload
Sensations	Vision, hear- ing, touch, smell, taste, balance	Touch, taste	Touch, taste, pressure tempera- ture, balance, pain, propriocep- tion, interocep- tion	Vision, hearing, touch

Figure 2. Categorization of sensory descriptions in ten autobiographies by persons diagnosed with ASC.

In the second qualitative analysis (study II) the inductive approach allowed more aspects related to sensory reactivity to emerge. In the interviews seven higher order sensory categories were developed (table 6) and the variations of sensory reactions in study I were confirmed. Hyperreactivity was mostly found in auditory visual and touch stimuli and hyporeactivity comprised mostly interoceptive, thermal and pain stimuli. Issues with regulation of attention and compensating/ coping strategies related to sensory processing were not specifically probed in the interviews but were discussed by many participants (table 6).

Table 6 Sensory-reactivity experiences described by 15 individuals with autism spectrum conditions

Categories	Subcategories	Number of statements	Number of interviews with statements
Being hyper-reactive to stimuli	Reacting overly strongly to specific stimuli	114	15
	Noticing small or unusual aspects of stimuli	32	9
Being hypo-reactive to stimuli	Being long term hypo- reactive to specific stimuli	35	12
	Being temporarily hypo- reactive	5	3
Reacting with general overload from too	Becoming overwhelmed by stimuli from environments	20	7
much stimuli	Becoming overwhelmed by prolonged aversive stimuli	7	5
	Becoming overwhelmed by stimuli from people	17	8
Having strong stimuli preferences	Strongly preferring certain stimuli qualities	29	13
•	Strongly preferring same- ness in stimuli	12	8
Managing attentive- ness to stimuli	Being unable to filter out stimuli	8	4
	Being unable to focus on stimuli	12	7
Managing senso- ry/motor stimuli	Having poor, exceptional and varying control and coordination of body	20	8
	Having poor balance	3	3
Dealing with consequences of sensory	Having sensory-related problems with daily rou-	35	12
reactions in daily life	tines, using compensation strategies	39	12

Quantitative study results

Our aim for study III was to develop and pilot test a self-report questionnaire for sensory reactivity based on the qualitative studies. The developmental process has been described under the heading "Development of the instrument - Sensory Reactivity in Autism Spectrum SR-AS" above.

Exploratory and confirmatory factor analyses

The results of EFA showed that general overload and hyperreactivity items were strongly correlated and loaded together on a single factor, hyporeac-

tivity and sensory motor items roughly loaded on separate factors while the sensory interest items did not cluster to a separate factor. Six items were removed after EFA (see under the heading "Quantitative methods and data analysis" above). The remaining 32-item scale was tested by means of CFA. CFA assesses how well a hypothetical model fits the observed data. Factor models suggested in the EFA were compared to evaluate which model best fitted the data.

Table 7 shows essential fit indices that should be reported and interpreted when accounting for the results of CFA. The model Chi-square, or alternatively the model Chi-square by its degrees of freedom (Carmines & McIver, 1981) is the most basic fit statistic and should always be reported. The Chi-square/df-ratio reduces the effect of sample size compared to chisquare. It is a "badness of fit" index because the higher its value, the worse the tested model fits the data. The null hypothesis is tested that the model has a perfect fit to the population. A failure to reject the null hypothesis supports the tested model. The CFI is the relative improvement in fit of a tested model compared with a baseline model, also called the null model, which assumes zero population covariance among the observed variables. A rule of thumb for the CFI is that values greater than roughly 0.90 indicate good fit of the tested model (Hu & Bentler, 1999). The root mean square error of approximation (RMSEA), with its 90% confidence interval, measures error of approximation, and is therefore also referred to as a population-based index. Acceptable fit is an upper CI limit of equal to or less than 0.08 (Browne & Cudeck, 1993). The RMSEA is a "badness of fit" index in that a value of 0 indicates the best fit and higher values indicate worse fit. The standardized root mean square residual (SRMR) is based on transforming both the sample covariance matrix and the predicted covariance matrix into correlation matrices and on assessing the overall difference between the observed and predicted correlations. Values of the SRMR of equal to or less than .08 are considered good fit (Hu & Bentler 1999). There were only small differences between three, and four factor models but the four-factor model was found to yield the best fit.

Table 7 Model fit indices in CFA (n=233) Models CFI **RMSEA SRMR** χ2/df-ratio 2.5 0.58 One-factor .85 .08 - .09Three-factor 2.3 .07-.08 0.54 .88 Four-factor 2.2 .88 .07-.08 0.53 Recommended >.90 <.08 <3 <.08 values

Note: CFA, Confirmatory factor analysis. χ 2/df-ratio, chi square divided by its degrees of freedom. CFI, Comparative fit index. RMSEA, Root mean squared error of approximation. SRMR, Standardized root mean squared residual. Bold-face indicates best-fitting model.

The four-factor model is theoretically more comprehensible than the three-factor model. The Chi-square/df-ratio was considered good fit (Carmines & McIver, 1981) as well as the SRMR (Hu & Bentler 1999). RMSEA met criteria for acceptable fit with an upper CI limit of equal to or less than 0.08 (Browne & Cudeck, 1993). CFI showed borderline fit (Hu & Bentler, 1999). Factor loadings ranged between 0.47 and 0.86 in the high awareness hyperreactivity factor, between 0.45 and 0.80 in the low awareness hyporeactivity factor, between 0.66 and 0.78 in the sensory interests factor and between 0.76 and 0.83 in the sensory/motor factor. Correlations between factors were high between 0.82 and 0.96.

Table 8 shows the content of the 32-item scale. In the Appendix 1 the final 32-item scale is presented and the scoring scheme for SR-AS is shown in the Appendix 2.

Table 8 Sensory Reactivity in Autism Spectrum SR-AS1

Table 8 Sensory Reactivity in Autism Spectrum SR-AS ¹					
Factors/subscales and items	Facets				
High awareness/Hyper-reactivity (1, 3, 6, 7, 11, 12, 14, 17, 18, 20, 22, 25, 30, 32)	Overly strong reactions to specific stimuli Noticing small or unusual aspects of stimuli Becoming overwhelmed by stimu- li from people, environments or pro- longed aversive stimuli				
2. Low awareness/ Hypo-reactivity (2, 4, 8, 10, 16, 23, 26, 27, 28, 31)	Long term or temporary lack of registra- tion, discrimination or recognition of specific stimuli				
3. Sensory interests (15, 19, 24, 29)	Preference for certain stimuli qualities Preference for same stimuli				
4. Sensory/motor (5, 9, 13, 21)	Problems with control of body and balance				

1The questionnaire and scoring scheme are attached in the Appendix 1 and 2

Reliability and discriminatory power of the SR-AS scale

Reliability in the form of internal consistency (Cronbach's alpha) for the total SR-AS was 0.96. Alphas for subscales scores were: high awareness/hyperreactivity 0.93, low awareness/hyporeactivity 0.89, strong sensory interest 0.80 and sensory/motor 0.89.

The discriminatory power or criterion validity of the scale was assessed using the area under the curve (AUC; figure 4). The AUC can take any value between 0 and 1. The closer AUC is to 1, the better the overall diagnostic performance of the test. The AUC estimates the probability that a randomly selected individual will be correctly rated by the test. The AUC for SR-AS was 0.93, CI: 0.89–0.96. The ROC analysis indicated that the questionnaire accurately distinguished the ASC sample from the population sample.

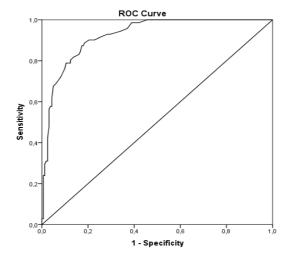


Figure 3. Receiver operating characteristics of the Sensory Reactivity in Autism Spectrum (SR-AS).

Sensory clusters

To identify subgroups of people with similar sensory features in the ASC sample and in the population sample separately (Study IV) we applied the SR-AS conducting hierarchical cluster analysis, using Wards method with the squared Euclidean distance measure. The agglomeration coefficients and dendrogram generated by the cluster analysis suggested a three cluster solution in the ASC sample (table 9).

Table 9 Mean scores (standard deviations) of subscales across clusters in the ASC

sample (n=71)

Jampio (III-71)					
	ASC clus-	ASC cluster2	ASC clus-	ANOVA	Effect
	ter1	n=17	ter3		size
	n=37	Intermediate	n=17		
	Low		High		
Subscale	M/SD	M/SD	M/SD	F	η2
High aware- ness/ hyperreactivity	1.15/0.60ª	1.60/0.55b	2.29/0.38°	25.186***	0.43
Low awareness/ hyporeactivity	0.78/0.47ª	0.96/0.45ª	1.91/0.54 ^b	32.401***	0.49
Sensory interests	1.01/0.54ª	1.40/050b	2.28/0.50°	32.401***	0.50
Sensory/motor	0.49/0.39	1.81/0.39 ^b	$2.41/0.59^{\circ}$	105.500***	0.76

Note. For all F statistics df is 2, 70.

Cluster one (52 % of the ASC sample) represented a mild elevation of atypical sensory reactivity on all subscales, sensory/motor issues, in particular, were uncommon (figure 4). The intermediate cluster (24 % of the ASC sample) had significantly elevated scores on all subscales except hyporeactivity. The third cluster (24 % of the ASC sample) represented the highest sensory reactivity on all subscales and was the only cluster with evident concurrent hyper- and hyporeactivity. The three-cluster solution was checked with a k-means cluster analysis and 96 % of the participants in the ASC group kept their cluster membership in the K-means three-cluster solution.

a,b,c Clusters with different letter superscripts are significantly different by Tukey post-hoc comparisons.

^{***}p < .001.

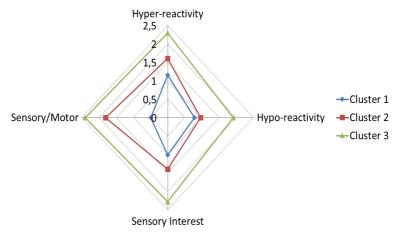


Figure 4. Mean scores of SR-AS subscales across clusters in the ASC sample

Two clusters best fitted the data in the population sample (table 10). A first large cluster of low scorers (84% of the sample) and a second small cluster of high scorers relative to the other cluster (16% of the sample). All factors differentiated significantly between the two clusters (Mann-Whitney U test, p < .001 for all comparisons).

Table 10 Mean scores (standard deviations) and medians of SR-AS subscales across

clusters in the population sample n=162)

	Cluster 1		Cluster 2			
	Minimal		Quite low	_	Mann	Ef-
	atypical sen-		atypical sen-		Whitney	fect
	sory reactivity		sory reactivi-		<i>U</i> test	size
	n=136		ty* n=26			
Subscales	M/SD	Mdn	M/SD	Mdn	z U	r
High awareness/	0.30/0.30	0.21	1.03/0.50	0.89	-6.80***	.53
hyper-reactivity					283.50	
Low awareness/	0.15/0.16	0.10	1.00/0.51	0.90	-7.92***	.62
hypo-reactivity					66.50	
Strong sensory	0.22/0.29	0.00	1.26/0.55	1.30	-7.87***	.62
interests					130.50	
Sensory/motor	0.14/0.24	0.00	0.96/0.72	1.00	-6.64)***	.52
					477.50	

p < .001

In the k-means cluster analysis of the population sample, 99.91 % of the participants kept their cluster membership.

DISCUSSION

The discussion of results is followed by a discussion of methods, theoretical considerations, conclusions, implications and suggestions for further research

Discussion of results

High sensory awareness and hyperreactivity can be a direct cause of distress and sensory overload and result in limitations in work, family and leisure activities through avoidance strategies and withdrawal. Hyporeactivity can lead to indistinct physiological feedback and create difficulties for every-day activities and potential health problems.

Perception in the human sphere is very demanding because of the need for multisensory processing and rapid interpretation as exemplified by Lawson (2003): "Although it is still easier to hear people when eye contact is avoided. I do attempt to look at them during conversation. I accept this is a social norm in Western cultures" (p. 11). Stephen Shore (2003 p. 143) explains: "With people having autism and Asperger Syndrome, however, the nonverbal component can be so difficult to decode that it interferes with getting meaning from the verbal channel. As a result, very little, if any, communication occurs."

A person with ASC must interact despite lack of cues from facial expressions, gestures, tone of voice, and overall body language. Too much weight can be placed on the verbal expressions or on details in the verbal code so that the essential message is missed. One informant commented on speech perception "I know what I send but I never know what I receive". Problems in imagining how one's own interaction will be received and interpreted aggravate the difficulties. The information normally received from the way others mirror oneself is lost. Precise verbal communication should be understood as a necessity and not as a chosen preference.

Sensory reactivity seems to be inherent in a more complex process than that captured in DSM-5 or in the SR-AS. However, it was possible to disentangle most frequently self-reported sensory problems described by adults with ASC. The SR-AS is designed to serve as a clinical tool for identifying atypical sensory reactivity in adults referred to neuropsychiatric assessments. It is also intended to be used for self-knowledge and subsequent development of coping and compensating strategies and to reveal needs for adaptions of the environment needed both in daily life and in health care situations. The SR-AS has a promising validity and reliability.

There are no prior validated self-report instruments tailored from the experiences of adults with ASC.

Qualitative results

In the autobiographical texts it was clear that all the authors of autobiographies aimed to convey to the reader the full experience of living with ASC. The significance of being different with respect to sensations, perceptions, thoughts, emotional processes and relationships was stressed. An often metaphorically expressed obstacle: "glass", "film" (Lawsson, 2003), "sarcophagus" (Brattberg, 2003), "wall" (Shore, 2003) describes the feeling of living in a separate reality while concurrently feeling unprotected from the "real" world and without filters against intrusion from the environment.

The distress resulting from hyper-reactivity and sensory overload is central. Expressive language was used to describe hyper-reactivity in terms of reacting with pain, anguish or full blown panic, for instance, to specific sounds. Pleasurable sensory experiences were also vividly described. Sensations in general seem to have a stronger and sometimes disruptive impact compared to the way they are felt by people without ASC. The need for coping and compensating strategies are inherent in the descriptions. Hyporeactivity is fairly common in our qualitative studies, while only one other qualitative study by Robledo et al., (2012) has described the same phenomenon of persistent hyporeactivity in some senses. Perhaps this is because the consequences of hyporeactivity are less obvious for those affected and therefore not spontaneously voiced unless probed. The effects are secondary, not being aware that one has been hurt for instance or not feeling signals from the body, like hunger. Obviously the impact of not feeling is less acute than experiencing pain or anxiety from hyperreactivity. In our research we showed that hyporeactivity causes problems with every-day routines like knowing when it is time to eat or rest. We have also described fluctuating sensory reactivity, like temporary hyporeactivity to sound and visual stimuli due to sensory overload or stress (study I) also described by Bogdashina (2003). Finally we would like to point out that interest in sensory experiences and seeking them out descibed by our participants and sources were urges for highly specific stimulation that could be present both in a person's hyperreactive and hyporeactive modality. The hunt for them was sometimes developed into deep involvements and advanced interests. This is very different to the

sensory seeking items in A/ASP (Brown & Dunn 2002) that are based on the high sensory thresholds, causing a general urge for stimulation.

Quantitative results

CFA resulted in four correlated subscales. The empirical support for the four factor model suggests it is appropriate to use the separate subscales rather than the total scale, since combining factors into a single, aggregate score is not the best way to represent an individual score on the SR-AS. Previous study results on the underlying structure of sensory reactivity in adult samples vary. A one-factor model for hyper- and hyporeactivity items was shown to best represent the data in the newly developed GSQ (Robertson & Simmons, 2012), but it should be noted that the analysis was performed on data from the general population with probably less variance in the responses. In the research on the factor structure of the A/ASP a four-factor structure was retained after some adjustments: low registration, sensory seeking, sensory sensitivity and sensation avoiding (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001).

The cluster analysis for the ASC sample resulted in two distinct high and low subgroups and an intermediate subgroup. There were qualitative differences with sensory motor issues being very uncommon in the low reactivity subgroup and combined heightened hyper- and hyporeactivity evident only in the high frequency subgroup. There are similar overall patterns in prior analyses of parent-reports (Ben-Sasson et al. 2008; Ausderau et al., 2014) resulting in high and low subgroups and varying intermediate subgroups. The results of our study further resemble the Ausderau et al. (2014) study with respect to a definite co-occurrence of elevated hyper and hypo-reactivity, only in a high frequency cluster.

The result in the population sample of 16 % with elevated scores is in accordance with heightened sensory reactivity investigated by Aron and associates (Aron & Aron 1997; Aron, Aron, & Jagiellowicz, 2012) in a series of studies using the Highly Sensitive Person Scale (HSPS). They defined sensory processing sensitivity as sensitivity to internal and external stimuli, including social and emotional cues and stated that it is a relatively common trait in the general population. In studies conducted with the HSPS (2000 respondents in total), between 10% and 35% of the respondents were highly sensitive (Aron et al. 1997; 2012). As Liss, Mailloux and Erchhull (2008) pointed out, people with autistic-like traits do not easily discern social subtleties, as people who are highly sensitive are supposed to do according to the HSP concept. Some people who are highly sensitive in

the general population may have traits according to the HSP concept and be sensitive to social cues as well, while some have autistic-like traits and are sensitive only to physical stimuli and not to social stimuli.

Methods discussion

General design

The design of the thesis is a combination model of qualitative and quantitative studies in sequence (Mayring, 2007). The qualitative exploratory first steps informed the development of the instrument tested and used in the second quantitative exploratory, confirmatory and application steps of the research. An integration of qualitative and quantitative methods allowed for the individual perspective to complement the group comparison perspective in the quantitative approach.

Qualitative methods

Qualitative CA was used in both study I and II. Qualitative CA was chosen on the grounds that our text material was concrete and therefore appropriate for CA, which often deals with a basic level of systematizing content, finding patterns, concept development, or at the most, model building (Lindkvist, 1981).

It was intended to balance any potential limitations of the deductive approach in study I by making the second study inductive. Qualitative studies with different sources enabled us to obtain variation across contexts, participant's (sources), demographics and time periods. The ranges in study I and II were similar with some individuals experiencing only hyperreactivity, in few sensory channels at one extreme, and at the other end individuals who experienced both hyper- and hypo-reactivity in multiple sensory channels, strong sensory interests of several kinds and sensory/motor issues. In addition the verbal expressions were similar across individuals and samples, using strong vivid verbal expressions. Therefore we judged the combined data of study I and II to be sufficient to capture the range of atypical sensory reactivity and the sensations likely to give rise to fascination and strong sensory interests. At the same time it is important to remember that each individual experience is unique and it is not possible to capture all potential reactions. We endeavoured to cover those that are most common in adults.

The selection of context and participants and gathering data that fit the purpose of the study is essential for trustworthiness of qualitative research (Lincoln & Guba, 1985). Credibility (equivalent to internal validity in

quantitative research) as an aspect of trustworthiness was underpinned by peer debriefing in which the research process was discussed with colleagues who are experienced with qualitative methods. Other techniques for credibility were triangulation of sources and methods used in the qualitative studies I and II (Lincoln & Guba, 1985) and member checks. A member check is a process where members of the group from which data are gathered, check the data, interpretations and conclusions. A member check was made later in the research process, when the items developed from the qualitative findings, were reviewed by members of the target group. Another aspect of trustworthiness is dependability (equivalent to reliability in quantitative research) where it is essential to ensure that the categories created and the interpretations cover the data. This was addressed through calculating inter coder reliability (percent agreement) in study I, and checking the categories created by a co-researcher experienced in qualitative research in study II. Transferability (equivalent to external validity in quantitative research) of the results to other contexts was aimed at through collecting data from adequate and varied samples (Malterud, 2001). By giving the informants' characteristics we make it possible for readers of the studies to judge to what contexts the findings can be applied. We aimed to offer clear descriptions of the methods used for gathering, data, data analysis, and interpretation and provide quotations to confirm all categorizations and facilitate confirmability (objectivity in quantitative research) which is linked to the repeatability of studies. We also sought for reflexivity in the research process (Malterud 2001) by identifying preconceptions discussed in the limitations and strengths section below.

Instrument development

Friedenberg (1995) identified three approaches to scale development: rational, theoretical, and empirical. The last of these comprises criterion group and factor analysis methods. In the rational approach the construction of items is based on the judgments of the person who develops the scale and items are seen as obviously related to the characteristics being measured. The theoretical approach uses theory to determine the content of the scale items. In the empirical approach statistical analyses of item responses are used. Often these approaches are combined. What is crucial in test development according to Standards for Educational and Psychological Testing (American Psychological Association 2014) is to state clearly the purpose and framework of a test and develop specifications

before development and evaluation of items and scoring principles. In our research we used qualitative research to ground the purpose and framework of the test before developing items and after this items were empirically evaluated by factor analysis.

Quantitative methods

Validation of the SR-AS

A broad definition of the validity of an instrument is "how well it measures what it purports to measure" (Nunally & Bernstein, 1994, p. 83). In the present research content validity was first evaluated, the accuracy of the sampling of items was evaluated, based on agreement between authorities (ibid).

Subsequently construct validity was appraised in the form of EFA and CFA. For exploration of the underlying structure of items with an exploratory method we chose common factor analysis (FA) over principal-components analysis (PCA; Hair et al., 1995). PCA analyses all variance whereas FA analyses only shared variance and the latent factors produced by FA account for the shared variance among items. FA therefore seemed to best fit the purpose of validating a new scale (however it should be noted that PCA and FA often produce similar results). The choice of an oblique rotation (promax) method for the extracted factors in the EFA was due to factors being intercorrelated. A competing-models approach was used in CFA to confirm or disconfirm the predetermined models decided by the researcher.

The sensory constructs from the CFA partly overlap the constructs in the DSM (hyper-and hyporeactivity and sensory interests). A problem with factor analyses of sensory reactivity in adults is that samples comprised volunteer participants, mostly students (Brown, Tollefson, Dunn, Cromwell & Filion, 2001), and volunteer samples on line (Tavassoli T, Hoekstra RA, Baron-Cohen, 2014). To our knowledge, no factor analysis of sensory reactivity with adult participants has been conducted exclusively on data from participants with a confirmed ASC diagnosis.

Finally it was assessed how well the instrument produced predicted group differences using AUC. According to the Standards (2014) criterion validity involves investigating if a test predicts a hypothesized outcome or criterion.

Assessing reliability of the SR-AS

Reliability was assessed with internal consistency (Cronbach's alpha) of items in the total scale and subscales, which is a measure based on average correlations between items (Nunally & Bernstein, 1994). Consistency can also be measured by using a parallel form of a test and calculating the correlation of the parallel form and the test (Nunally & Bernstein, 1994). We judged this approach too time consuming and The Standards (APA, 2014) state that an internal consistency estimate with coefficient alpha is an appropriate reliability assessment

Cluster analyses

Exploratory factor analysis and cluster analysis are both independent multivariate techniques where all variables are considered simultaneously without being split into dependent and independent variables. Factor analysis is variable oriented, whereas cluster analysis is a person oriented multivariate analysis. The idea behind person oriented statistics is to study whole individuals as opposed to the study of separate variables (Bergman & Magnusson, 1997). The focus is on how the individual profiles differ between groups. This aim mirrors clinical efforts to capture similarities and differences between individuals when trying to understand patients and their symptom profiles in every day clinical practice.

Theoretical considerations

Leekam pointed out the lack of research into attempts to integrate the criteria in the second dimension of ASC (Leekam, 2011), as well as lack of attempts to integrate the social-communication aspect (first dimension) and non-social aspects (second dimension) of ASC (Leekam, 2016). By definition the two dimensions need to co-occur and yet surprisingly little research addresses this. From a clinical point of view when trying to understand the individual as a whole, fragmentary research without attempts to integrate results is less helpful. Much research focus has been on defining the primary symptoms as opposed to the secondary symptoms, a hierarchical integration of the different features of ASC. Leekam proposes integration models that focus more on how different features are linked and interplay (vertical integration). Leekam stresses that a developmental frame is central to this approach. A thought that was important already in Kanner's first account of autism. In clinical practice the whole nature of the individual situation needs to be understood for decisions on interventions to improve quality of life and outcome for the individual.

In the assumptions below we account for our reasons for linking developmental aspects, sensory processing, perception, executive functions as an aspect of cognition, attention and the use of repetition and routine.

Sensory systems become increasingly refined during development with broadening of multisensory perceptual capacity (Burr & Gori, 2012). Recent research indicates that there are also narrowing processes. Young infants are broadly perceptually tuned and tend to respond indiscriminately to all perceptual inputs (Lewkowicz, 2014). The narrowing processes lead to increased perceptual sensitivity and responsiveness to stimuli in the individual's physical and social environment while they decrease for other stimuli.

Sensory level bottom-up perception represents the information in the neural signals from the receptors to the brain (figure 5). This lower level of perception is bottom-up, automatic, stimulus-driven and involuntary, driven by properties of stimuli themselves, to enable selective attention to, and focus on what we choose and suppress attention to other stimuli (Diamond 2013; Theeuwes, 2010). This filter, here called selective attention, receive all stimuli, but those we do not want to attend to are blocked out, for instance in situations when several people are talking and we want to concentrate on one voice. This automatic attentional control seems to be limited in ASC as was illustrated in the interview study II: "I observe a lot of things that are probably unnecessary for other people who perhaps focus on what they need to concentrate on for this particular thing in this context, but often I can see everything else around it as well ... I don't filter so I can hear you just as well as the fan all the time. I don't exclude it".

In this thesis we showed that a group of adults with ASC reported problems with vague awareness of interoceptive stimuli, including, hunger, satiety, tiredness, and temperature, besides being hyporeactive to pain. Bottom-up detection of bodily states seems to be diminished, but it is harder to link hyporeactivity to explanatory theoretical concepts. However, there are neurobiological explanations of low body and interoceptive awareness in ASC. Fiene and Brownlow (2015) suggest low activity levels in the anterior insula. It has been proposed that the anterior insula is implicated in functions including interoceptive awareness in typical development (Menon & Uddin, 2010).

Cognition is a very broad concept relating to any form of knowing (memory, perception, language, executive functions and attention; VandenBos, 2007). Diamond (2013) defines and describes executive functions

(EFs) in a developmental frame, maturing during both childhood and adolescence. EFs refer to a range of top-down mental processes used when concentration and attention are required (figure 5).

Selective attention can also be top-down and voluntary, when we choose to ignore and inhibit attention to some stimuli and attend to others based on our goals or intentions (figure 5). Selective or focused attention on this higher level is top-down attentional control, an active, goal-driven executive control (Diamond, 2013; Theeuwes, 2010). Top-down regulation of perceptual flow, based on expectancy and goal set also function differently in ASC.

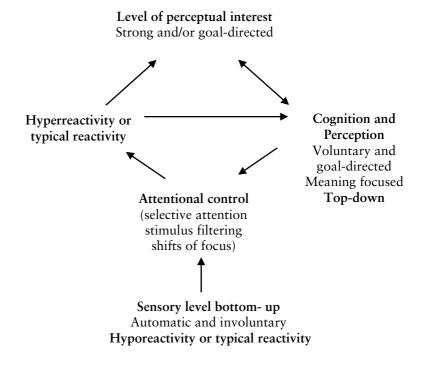


Figure 5. A working model for atypical sensory reactivity

In enhanced perception and hyperreactivity, the focus of attention was described as narrow and sharp, and a feeling of being stuck in the ongoing sensory perceptual experience is conveyed (study I). In typical develop-

ment there is at young age a tendency to continue to focus attention on what has previously been experienced as relevant. This tendency alters during development but does not disappear completely. A child of 3 focusing on the "redness" of a red truck has difficulty to switch mind-set and focus on its "truckness" instead. The child gets stuck in the previous way of thinking about the stimuli (Diamond, 2013). It is possible that this feature of being stuck in the sensory perceptual actual experience is sometimes extant in ASC in adulthood. Such tendencies might also partly explain sensory interests that involve intensive long standing sensory experiences. We assume that hyper- and hyporeactivity combined with limited bottom up and top down attentional control and deficits in ability to quickly shift attentional focus are parts of the explanation of the preference and need for routines, predictability and consistency of the environment.

Clinical implications and use of the SR-AS

The scoring scheme of the SR-AS (Appendix 2) provides an overview that can be used for discussion with patients about their individual sensory reactivity profile. Individuals with ASC can utilize very different sensory perceptual processing for different senses and even for the same sense some classes of stimuli can be very disturbing while others are not. Therefore the mean score of the SR-AS is not so relevant in clinical evaluations. Visual and auditory hyperreactivity, enhanced perception as well as problems with persistent stimuli, potentially create problems with some physical and social surroundings causing sensory overload and anxiety. Touch hyperreactivity is of course an issue in relations to other people e.g. affective touch or unknown people coming too close. Hyperreactivity to smell, flavour and food consistency can lie behind a limited food repertoire, potentially causing mild to severe problems. A balance between food selectivity and health aspects can be discussed. It may be possible to influence sensory motor issues with balance and motor control through physiotherapy. Difficulty in sensing internal bodily states is reported by the participants in the qualitative studies (I and II) to cause problems in every-day routines.

In clinical encounters, it is often good to start a dialogue with a patient on concrete matters like sensory issues. It is easier to talk about sensory reactivity than social interaction which is more complicated and delicate. Below are our suggestions on topics for discussion.

- An overall coping/compensating strategy is to reflect on properties
 of the environment e.g. noise, light, temperature and how the visual environment is organized. Minimize unnecessary visual and auditory stimuli. Organize the visual environment in a logical way.
 Reflect on adaptations in the learning and work environment.
- In a situation that gives rise to feelings of paralysis or stress, always ask: "what is bothering me?" This develops the ability to identify the stressor. Torbjörn Andersson (2009), himself diagnosed with ASC, points out enhanced awareness as the approach to handling perceptual stressors for individuals with ASC and average or above average intellectual ability.
- Mindfulness-like strategies can be used to increase awareness (Andersson, 2009). Listen to the acoustic environment and identify noises that are stressors like background noises, mechanical noises, traffic noise, and high frequency noises. Inspect the visual environment, is it cluttered with too many things, shapes, colours and patterns or people continuously moving? Is the lighting too bright? Investigate the types of stimuli that can trigger a reaction.
- Food selectivity is sometimes problematic as it can have several roots, investigate what is disturbing.
- Think about potential aids for avoiding too many stimuli and reflect on use of visual or written support/ individual schedules that include sensory issues.
- Strategies to cope with every day stress can be developed through creating activities and routines, every day rituals save energy (Andersson, 2009).
- Reflect on sensory or other aids that have a calming effect in moments of stress. Sensory aids are of course individual, they could for instance be the feel of soft material or repetitive movement like sitting in a rocking chair. Use a calm distraction-free space for calming the senses.
- Acceptance of and communicating one's experiences of sensitivity
 to others that are closely involved can be a good aid, so that they
 are aware of any problems that may arise. Explain the need to take
 a break.

- Models can be used to picture a stressful situation for example how large a percentage of my full capacity is occupied by the perceptual stressor or how much does this particular coping strategy cost me in relation to how much I gain from it (Andersson, 2009).
 Such strategies facilitate efforts to reduce problems in a clear and visible way.
- Think about sensory interests that can stimulate motivation and might develop into deeper interests.

Limitations and strengths

Sensory issues were ascertained subjectively and not from observations. This limitation is inherent in the complete adherence to the insider perspective and can also be viewed as strength. It is clear that we aimed to capture what is commonly reported subjectively by the target group and not what is reported by parents or clinicians, for instance.

The perspective of the observer is always limited somehow and determines what can be seen (Haraway, 1991; Malterud, 2001). My preconceptions that the overall perceptual and sensory experiences of people with ASC differ from those of TDs' influenced the decision to investigate sensory reactivity as well as the adoption of an inside perspective in the studies. The methods used for collection of data in the qualitative studies were influenced by my preconceptions of communication difficulties in ASC. My professional experience had an impact on how the interviews were planned and conducted. Qualitative data were gathered in the interview study with more precise questions than those usually employed in qualitative studies. This was due to the literalness inherent in ASC, which in my judgement requires more precise communication. This was compensated for in study I through collecting data from descriptions by people who had themselves chosen to communicate their experiences without any prompts. It can be difficult to get so called "thick descriptions", which are the basis of qualitative research from people with ASC because of problems with spontaneous communication. Therefore we used what was already there, i.e. the wealth of autobiographies by people with ASC. I agree with Malterud (2001) that knowledge is partial and situated, therefore the impact of the researcher should be reflected on and accounted for. Subjectivity arises when the researcher's impact is ignored and hidden (ibid). In qualitative studies different researchers might access different, although equally valid representations of phenomena, depending on their positions and perspectives.

The studies in this thesis recruited individuals from psychiatric and habilitation services, and the ASC participants may not be representative of the population of adults with ASC diagnoses. All participants belong to the high functioning end of the spectrum and 85% reported psychiatric comorbidity. Furthermore the majority received their ASC diagnosis in adulthood. The use of the instrument may be limited to the intended population, namely a group of adults referred to psychiatric evaluation on suspicion of a neuropsychiatric condition.

According to the Standards for Educational and Psychological Testing (APA, 2014) a sample for evaluating items should be as representative as possible of the population for which the test is intended. The ASC sample size was not large enough to enable factor analyses to be conducted in this sample alone. The factor analyses were performed in a merged sample of ASC and general population participants. This may have influenced the results of factor analyses because the overall variance in the responses from the general population sample was different from the variance in the ASC sample. The decision to include the comparison sample in the factor analyses is a limitation but judged to be acceptable on the ground that atypical sensory reactivity also occurs in the general population. This is in line with the idea that autistic-like traits in the general population are on the same continuum as the characteristics of ASC (e.g. Constantino & Todd, 2003) and that they share the same aetiology (Lundström et al., 2012). This may also be applicable to sensory issues. Two recent studies found a positive correlation between hyper- and hyporeactivity and autistic-like traits in a population sample (Horder, Wilson, Mendez, & Murphy, 2013; Robertson & Simmons, 2012).

If the scale had been validated on an ASC sample and a comparative clinical sample with other psychiatric diagnoses, the research context would have greater resemblance to clinical conditions for which the scale is intended. Sensory issues can be expected to be more frequent in a clinical sample than in a sample from the general population and the differences between samples would have been smaller. For instance the shape of the ROC curve would have been different. When comparing a clinical diagnostic sample with a sample from the general population the results of the AUC will show too high a degree of discriminative power that does not mirror clinical reality. The clinician is rarely asked to distinguish between ASC and no mental health issues at all, but to differentiate ASC

from a range of other psychiatric diagnoses. It should be noted that the ROC curve was not conducted for the purpose of showing the diagnostic validity of the scale, or to provide cut scores, but was used as a crude measure of the criterion validity. According to the Standards (2014), criterion validity involves investigating if the test is a predictor of a hypothesized outcome.

The total scale internal consistency was very high (alpha 0.96). Results above 0.95 could indicate scale redundancy, rather than good psychometric properties (Nunally & Bernstein, 1994). Subscale internal consistencies were adequately strong, varying between 0.80 and 0.93.

The empirical support for the four-factor model suggests use of the separate subscales rather than of the scale's aggregate total. Since the scale is not intended to serve as a tool with a specified total score cut off to indicate significant sensory problems, this is not problematic in clinical use of the scale.

There may be discriminant validity problems with subscales due to high factor intercorrelations. The sensory interests factor in particular displays high correlations with hyper- and hyporeactivity factors. This is due to sensory interests items loading on hyper- and hyporeactivity factors and items with cross loadings. It was shown in our qualitative studies that sensory interests are connected to either hyperreactivity or hyporeactivity but sensory interests are on a different perceptual level that include higher order cognitive aspects and are theoretically best interpreted as variables in a disparate dimension. The sensory interests subscale has few items, and further development of the items and subscale may be needed. A discriminant validity testing of subscales in an ASC sample is warranted.

The psychometric evaluation is limited and concurrent validity (the strength of relationship between SR-AS and a previously validated measurement) and stability over time i.e. test-retest reliability (Nunally & Bernstein, 1994) were not checked. These are the most important validity and reliability checks yet to be conducted in order to further validate the scale.

Conclusion

Sensory experiences have a potentially strong impact on people with ASC and have a disruptive impact on their everyday lives. There is a need for an easy-to-administer clinical tool that captures a variety of common atypical sensory reactions experienced by people with ASC. The SR-AS identifies a wide range of relevant sensory symptoms. An important use of the SR-AS is to assess individual patterns of sensory reactivity for self-

knowledge and awareness, for development of coping and compensatory strategies and for information on environmental adjustments required. In diagnostic processes where other criteria for ASC are fulfilled clinicians are recommended to use the SR-AS to gather information on sensory reactivity for further discussion with the patient and to compare the results with the DSM-formulation of sensory symptoms.

After the inclusion of sensory issues in DSM-5 there will probably be a greater research focus on the sensory perceptual symptoms in the context of other diagnostic characteristics of autism. The links between sensory function subtypes, social function subtypes and restricted repetitive patterns are yet to be discovered (Leekam, 2016). Qualitative research to develop descriptions of these issues from the inside perspective is important as well as research on other levels. Another line of research that can advance theory on perceptual differences is longitudinal research on the development of perception in children with ASC compared to TD children.

There are no prior validated self-report instruments tailored for adults with ASC but even though the SR-AS offers promising validity and reliability, further assessment of psychometric properties are needed. Additional forms of reliability and validity and the identification of meaningful differences from other clinical populations also known to have unusual patterns of sensory reactivity are aims for further studies with the SR-AS tool.

SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)

Annorlunda responser på sensoriska stimuli har rapporterats hos nästan alla barn med autismspektrumtillstånd (AST). Fenomenet är mest undersökt hos barn och oftast med hjälp av föräldraskattningar. Några få studier indikerar att annorlunda sensorik består in i vuxen ålder och är vanligt även hos vuxna högfungerande personer. Ovanliga sensoriska responser har inte ingått i de tidigare diagnoskriterierna för AST. Dock i DSM-5 (2013) inkluderades hyper- och hyporeaktivitet och/eller ovanliga sensoriska intressen i kriterierna för AST.

Sensorisk hyperreaktivitet ger stress och sensorisk överbelastning som via undvikandestrategier och tillbakadragande kan begränsa arbetsliv, familjeliv och fritidsaktiviteter. Hyporeaktivitet medför oklar eller vag återkoppling från den egna kroppen som indirekt kan ge svårigheter med vardagsrutiner och utgöra en potentiell hälsorisk. Resultat av kvalitativa studier i avhandlingen indikerar att sensoriska symtom också indirekt påverkar social interaktion med höga krav på snabbt multisensoriskt processande. Starka sensoriska intressen är ofta en tillgång och medför inga direkta problem i den grupp som inkluderades i studierna (högfungerande som inte har något intellektuellt funktionshinder).

Det övergripande syftet med avhandlingen var att beskriva sensoriska fenomen från ett upplevelseperspektiv och att använda de personliga erfarenheterna hos personer med AST för att utveckla ett instrument som mäter de sensoriska symptom som är vanliga hos vuxna med AST diagnoser. I två kvalitativa studier (studie I och II) beskrevs fenomenen. En vid variation av hyper- och hyporeaktivitet över flera perceptuella modaliteter, sensomotoriska avvikelser samt starka sensoriska intressen beskrevs. Problem med att reglera uppmärksamhet samt problem att hantera sensorisk överbelastning diskuterades också av många deltagare i studierna. Från analyserna av beskrivningarna i de två kvalitativa studierna utvecklades frågor till ett mätinstrument. Frågorna reducerades i flera steg och den slutliga skalan Sensorisk Reaktivitet vid Autism Spektrumtillstånd (SR-AS) innehåller 32 frågor i fyra subskalor: hög medvetenhet/hyperreaktivitet (14 frågor), låg medvetenhet/hyporeaktivitet (10 frågor), starka sensoriska intressen (4 frågor) och sensomotorik (4 frågor). Skalan validerades i studie III i flera steg med innehålls- och faktoranalyser. Skalans förmåga att diskriminera mellan personer med och utan AST och dess reliabilitet (intern konsistens) undersöktes därefter (studie III). Resultaten visar lovande mätegenskaper hos SR-AS. I ett sista steg användes skalan för att identifiera kluster av sensoriskt fungerade med hjälp av hierarkisk klusteranalys (studie IV). Vi fann tre olika kluster med olika sensoriskt fungerande i gruppen vuxna med AST.

Avhandlingens bidrag till kunskapen om sensorik och perception vid AST är en presentation av de individuella erfarenheterna och perspektiven hos personer med AST och skapande av en lättadministrerad skala för att mäta sensoriska symptom som är vanliga hos vuxna med AST. SR-AS kan användas i flera syften: att i kliniska sammanhang ge en översikt av individuella sensoriska mönster, att öka patienters egen medvetenhet om sensoriska reaktioner, att utveckla hanteringsstrategier i vardagen, att reflektera över den sociala och fysiska miljön och möjliga anpassningar av den och att ge en grund för bedömning av om kriterier för sensoriska symptom vid AST enligt DSM-5 är uppfyllda. I diagnostiska processer där andra kriterier för AST är uppfyllda rekommenderas kliniker att använda SR-AS för att samla information om sensoriska symptom för diskussion med patienten och jämförelse med beskrivningar av sensoriska symptom i DSM-5.

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