

Autobiographical Accounts of Sensing in Asperger Syndrome and High-Functioning Autism

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Sensory experiences in Asperger syndrome (AS) or high-functioning autism (HFA) were explored by qualitative content analysis of autobiographical texts by persons with AS/HFA. Predetermined categories of hyper- and hyposensitivity were applied to texts. Hypersensitivity consists of strong reactions and heightened apprehension in reaction to external stimuli, sometimes together with overfocused or unselective attention. It was common in vision, hearing, and touch. In contrast, hyposensitivity was frequent in reaction to internal and body stimuli such as interoception, proprioception, and pain. It consists of less registration, discrimination, and recognition of stimuli as well as cravings for specific stimuli. Awareness of the strong impact of sensitivity is essential for creating good environments and encounters in the context of psychiatric and other health care.

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PROBLEMS WITH MODULATION of sensory input, “lack of responsiveness or an exaggerated reaction to sensory stimuli” (Ornitz, 1973, p. 26), have continuously been noticed since the first descriptions of the autistic spectrum. The characteristics of the autistic spectrum are limitations in social interaction, communication, and imagination, together with narrow repetitive behaviors (Wing, 1997). In Asperger syndrome (AS) or high-functioning autism (HFA), intellectual ability is average or high. The difference between AS and HFA is delayed childhood development in language or cognitive functions in HFA, but not in AS. Early descriptions noticed sensory modulation problems, for example, in relation to sound and touch (Asperger, 1944/1991; Wing, 1969). Sensory impairments are not diagnostic criteria in the American Psychiatric Association’s (APA, 1994) fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. In the forthcoming *DSM-V*, sensory “hyper- and hypo-reactivity” (APA, 2010) are proposed as subcriteria (to the criteria-fixed interests and repetitive behavior) for autism spectrum

disorder. Another proposed change is to include AS in the concept autism spectrum disorder.

Sensory phenomena have been reported clinically, but little research has been devoted to them (Happé & Frith, 2006). There are theoretical assumptions about the causes of sensory differences in autism, but there is no theoretical model that fully explains them (Gerrard & Rugg, 2009; Rogers & Ozonoff, 2005). The categories of hyper- and hyposensitivity broadly defined as over- and

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underresponsiveness, based on empirical ground, are used in scales developed to measure the phenomena. Scales are mainly parent report (Baranek, David, Poe, Stone, & Watson, 2006; Dunn, 1999; Talay-Ongan & Wood, 2000) or parent interview scales (Leekham, Nieto, Libby, Wing, & Gould, 2007). Dunn (1997) developed a theoretic generic model for sensory processing that is not specific to AS/HFA or autism. Low sensory thresholds are supposed to interact with behavioral responses and cause sensory avoidance or sensory sensitivity. Similarly, high sensory thresholds interact with behavioral responses and cause low registration or sensation seeking. Two scales for assessment based on this model were developed (Brown & Dunn, 2002; Dunn, 1999). High frequencies of modulation problems in children with autism compared with nonautistic children were found in research with parent report scales, and the same was seen in children with AS/HFA (Ben-Sasson et al., 2009; Dunn, Myles, & Orr, 2002). To the best of our knowledge, there is only one published quantitative study on the occurrence of sensitivity in adults with AS/HFA using self-report scale data and a nonautistic control group (Crane, Goddard, & Pring, 2009). This study showed the same pattern of high frequency of hyper- and hyposensitivity compared with controls as studies concerning children with autism and AS/HFA.

Sensory descriptions and measurements are mostly based on observation of childhood behaviors, and sensory modulation problems are inferred from these behaviors (Baranek et al., 2006; Talay-Ongan & Wood, 2000). Experiences that are verbally expressed and representative for the high-functioning group are sometimes referred to, but are often reported anecdotally, and systematic investigation is scarce. Two previous qualitative studies about sensory phenomena described by adults with AS/HFA have been conducted. One study analyzed Internet-based self-accounts by persons with AS/HFA (Jones, Quigney, & Huws, 2003), and one study analyzed published autobiographical material (Chamak, Bonniau, Jaunay, & Cohen, 2008). These studies provided examples of sensory and perceptual features, but there were not systematic analyses of different types of sensory reactions.

It is important to take into account verbal descriptions from high-functioning persons.

According to Billstedt, Gillberg, and Gillberg (2007), sensory and perceptual problems together with social interaction difficulties are the shortcomings most likely to persist into adulthood for persons diagnosed with autism in childhood. The aim of this study was to explore and describe hyper- and hyposensitivity in the context of verbal expressions of high-functioning persons with AS/HFA.

METHODS

Design

A documentary study with a qualitative descriptive design was conducted. Self-accounts by authors with confirmed diagnoses of AS/HFA were analyzed using content analysis in a sample of published autobiographies as data source. Content analysis is a method for making valid inferences from texts by classification of meaning into categories, created from the text content. Both manifest and latent content can be analyzed, and approaches can be deductive, inductive, or both, which means that analysis starts from a theoretical frame that can be developed (Krippendorff, 2004; Weber, 1990; Mayring, 2000). Documentary research (McCulloch, 2004; Scott, 1990) handle naturalistic data collected with minimal inference by researchers. There is a long-standing tradition to use content analysis with various kinds of documents (Krippendorff, 2004; Weber, 1990). In this study, a directed analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Mayring, 2000) was applied to explore the categories of hyper- and hyposensitivity in the context of autobiographical texts. Focus was on the manifest level of texts. Interpretation of an underlying meaning, referred to as latent level of analysis, was not appropriate or useful in the context of this study (Graneheim & Lundman, 2004; Sandelowsky, 2000).

Data Collection

References of autobiographies were found on the following Internet Web sites: [The Autism and Asperger Association](#), [National Autistic Society](#), [Autism Society of America](#), and [Neurodiversity](#). Seventeen works published in the Swedish or English language were collected and read, and 10 autobiographies were selected by Scott's (1990) quality criteria for assessing documents for research purposes. The criteria are (a) authenticity, (b)

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