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What Can We Learn about Autism from Autistic Persons?

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Key Words

Autism · Autobiographies · Perceptions · Representations · Nosography

Abstract

Background: To date, few studies have focused on the viewpoints of autistic persons themselves despite an increasing number of published autobiographies. The aim of this study is to highlight their personal experiences, and to compare them to scientific and medical knowledge and representations. **Method:** Adopting an anthropological approach, we analyzed 16 autobiographical writings and 5 interviews with autistic persons. We systematically screened this material and explored the writers' sociodemographic characteristics, cognitive skills and interests with a focus on their sensory-perceptual experiences and their representations of autism. **Results:** The authors' ages (22–67 years), their countries (n = 8) and backgrounds were varied, and most of them were high-functioning individuals with autism or Asperger syndrome. The most striking observations were that all of them pointed out that unusual perceptions and information processing, as well as impairments in emotional regulation, were the core symptoms of autism, whereas the current classifications do not mention them. **Conclusions:** Our results suggest that what has been selected as major signs by psychiatric nosography is regarded as manifestations induced by perceptive peculiarities and strong emotional reactions

by the autistic persons who expressed themselves. These considerations deserve to be taken into account by professionals to better understand the behavior and needs of autistic persons. We propose to include this point in the reflection on the next psychiatric classifications.

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Introduction

Autism is defined in both the international and American classification of diseases (ICD-10, DSM-IV) as a pervasive developmental disorder with onset before the age of 3, which involves deficits in social relationships, communication impairments, repetitive behaviors and restricted interests [1]. It is considered a syndrome more common in boys than girls. The symptoms were already described in the middle of the 19th century, notably by Jean-Marc Itard [2, 3]; however, autism was pinpointed as a disease in 1943 both in the USA by Leo Kanner [4] and in Europe by Hans Asperger [5–7].

The enlargement of the autism diagnostic criteria introduced in ICD-10 and DSM-IV in the early 1990s induced huge changes. Apart from nonspeaking and mentally challenged children, they also included children of average or superior intelligence displaying many autistic characteristics but no speech delay. According to the classifications, these children have Asperger syndrome [8].

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By including persons able to speak in the autism category, the classifications gave more people the possibility to adopt the diagnostic of autism. There is now a considerable number of published autobiographical and other first-hand accounts by persons with autism spectrum disorder (ASD) which provide valuable insights into both the nature and the subjective experience of autism, and which can be used as anthropological materials. Although some comments on the most popular biographies by Temple Grandin and Donna Williams [9, 10] have been published, we have failed to find any systematic study of the corpus as a whole.

The experience of autism was analyzed by some authors, but only in the case of 1 or 2 persons [11–13]. O'Neill and Jones [14] discussed sensory-perceptual abnormalities in people with autism based on published first-hand accounts and existing psychological research evidence. More recently, Jones et al. [15] conducted a qualitative analysis of 5 first-hand Web page accounts of sensory disturbances. Finally, Molloy and Vasil [16] analyzed the life story of adolescents diagnosed as having Asperger syndrome by conducting in-depth biographical interviews. In a similar way, our work focuses on the value of personal narratives. Whereas Molloy and Vasil were interested in the first generation of persons who grew up with the label of Asperger syndrome, we studied the accounts of adult autistic individuals who were not necessarily diagnosed as having autism in childhood.

Focusing on the narratives of adult autistic persons necessarily raises several theoretical and methodological issues. The objectivity of an experience which is solely seen through a person and her/his discourse may be questioned. Subjectivity is both the greatest strength and greatest weakness of these narratives [17]. Given that language serves the writers' wills and goals, how can one decipher what is really at stake? How can one pinpoint what is truly experienced? Analyzing biographies is complex, and even more so when dealing with persons suffering from mental disorders [18]. However, focusing on the autistic persons' views and stories validates their autonomy as human beings with their own thinking, sensibilities and feelings.

The aim of this study was to focus on the personal experiences of 20 autistic persons and to compare their views to the scientific knowledge available. To do so, we used a qualitative research design with the following questions. (1) What are their current situations in adulthood regarding social and family relationships? (2) What are the particular experiences (e.g. perceptions, intrapsychic experiences, affects) that could be relevant for clinical

and cognitive researchers? Unlike quantitative research, which sets a premium on reducing data to easily comprehensible units, our qualitative research attempts to document the complexity and multiplicity of experience [19].

Methods

Data Search

The references of autobiographies by autistic persons were found on the Internet (Web sites of parents' associations and autistic persons' organizations). Given that narratives evolve with time, we included the author's different books so as to underline possible changes or to collect missing data. We excluded books written through facilitated communication because the technique is suspected to reflect the beliefs and expectations of the facilitators. We collected 19 books by 15 persons with ASD. We tried to have an equivalent amount of accounts by males and females. In doing so, we noticed that given the male/female ratio of autism (4/1 and 8/1 for Asperger syndrome), more women express themselves in writing and publish it. Ten out of 15 were American biographies, so we decided to interview French-speaking persons in order to diversify the origin of the accounts. B.C. conducted 5 in-depth interviews with persons with ASD in Paris and Montreal. One of them (M. Dawson) did not accept to give autobiographical details but allowed us to take into account her political position concerning autism. Van Dalen's writings were also included because they contain precise descriptions of the detail-focused processing vision [20]. In total 21 accounts were collected (table 1).

Qualitative Research Design and Systematic Screening: Content Analysis

These accounts were treated as anthropological materials and studied as self-reported participant observations using a qualitative method. The main aim was to gather data that can be analyzed simultaneously. The complete process can be envisioned as circular rather than linear, with feedback loops affecting the ongoing research development [19]. The 2 researchers in charge of the study [21] started by reading the narratives. At the end of this generic data collection, they engaged in an attempt to synthesize all the data in a thorough description of the major themes that were used as the basis of a structured data sheet which provides the framework for systematically screening the biographies and interviews. All the books were read again by B.B. and B.C. to fill in the tables. This content analysis involves systematically distilling the massive amounts of raw data into a comprehensible description without losing the complexity inherent in the original material.

A traditional critique of qualitative research is that it may be unreliable, since interpretation is strongly bound by the theoretical presuppositions of the interpreters, who may be tempted to interpret data selectively to fit conscious or unconscious preconceptions [22]. To limit the investigators' bias we used a method involving 4 researchers from different disciplines (2 social scientists and 2 psychiatrists) who analyzed the same data sets and then compared the findings. The anthropologists constituted the first

Table 1. Sociodemographic characteristics and current status of 21 autistic persons (autobiographies or interviews)

Author and country	Sex	Birth	Current status	Diagnosis	Current activities
Schneider Edgar, USA	M	1932	remarried 3 children	nervous breakdown (46), schizophrenia (48), AS (63)	retired (computer science), autism conferences
Grandin Temple, USA	F	1947	single	autism (3)	Professor of zoology, autism conferences
Newport Jerry, USA	M	1948	married	AS (47)	writer on ASD subjects
Lawson Wendy, UK	F	1952	divorced 4 children	schizophrenia (18), AS (42)	social worker, autism conferences
Carpenter Anne, USA	F	1957		congenital rubella, autism (5 and 30) other labels: mentally retarded, emotionally disturbed, BPD	librarian for the Autism Society of Michigan
Holliday Willey Liane, USA	F	1959	married 3 children	exceptional child (3), AS (40)	psycho-linguist, autism conferences
Barron Sean, USA	M	1961	single	autism (4)	social worker for elderly people
Shore Stephen, USA	M	1961	married	autistic characteristics (2)	PhD in special education, experience in autistic self-advocacy
Williams Donna, Australia	F	1963	married	HF autism (26)	writer, artist, consultant in autism
Gerland Gunilla, Sweden	F	1963	single	ADD, AS (29)	autism professionals, autism conferences
McKean Thomas, USA	M	1965	single	PDD-NOS, autism (14)	poet, singer/songwriter, autism conferences, writer, ASA member
Sinclair Jim, USA	M	1965		autism (<6)	cofounded ANI, autistic self-advocacy, has pioneered the use of service dogs for autistic people
Segar Marc, UK	M	1974	single died in 1997	autism (7)	children's entertainer, autism consulting
Van Dalen J.G.T., Netherlands	M			autism	
Lee O'Neill Jasmine, USA	F			autism (26)	writer
Bouissac Joffrey, France	M	1980	single	autism (15)	open university courses
Huard Georges, Canada	M	1959	single	HF autism/AS (36)	computer science technician, ATEDEM and Satedi member
Dawson Michelle, Canada	F	1963	single	autism	autism researcher
Dubrulle Emmanuel, Belgium	M	1974	single	HF autism/AS (29)	computer science technician, Satedi president
Bernot Gabriel, France	M	1975	single	AS (28)	computer science researcher, Satedi member
Bonnot-Briey Stéfany, France	F	1976	single	eating disorders (13), mixed dissociation disorder, BPD, AS (26)	accompanies and educates autistic children, autism conferences, Satedi member

Figures in parentheses represent age. AS = Asperger syndrome; ADD = attention deficit disorder; BPD = borderline personality disorder; HF = high-functioning; PDD-NOS = pervasive developmental disorder – not otherwise specified.

Associations: ANI (Autism Network International); ASA (Autism Society of America); ATEDEM (Autisme et trouble envahissant du développement de Montréal); Satedi (Spectre Autistique Troubles Envahissants du Développement International).

data sheets including some authors' quotations. They were read by the psychiatrists; in case of contradictory views, consensus was reached through discussions after checking the original writings. Examples of quotations are given throughout the paper (the book references are indicated in the appendix).

The aim was to explore 2 main dimensions: (1) the writers' sociodemographic characteristics including gender, year of birth, socioprofessional status, current activities and remaining impairments as adults in the way they were described by the writers themselves, and (2) their sensory sensitivities and emotional reactivity, as well as cognitive skills and interests.

Results

Sociodemographic Characteristics and Current Status

Table 1 details the sociodemographic characteristics and the current status of 12 men and 9 women, 22–67 years of age (at the time of the first account), originating from various countries including the USA (n = 10), UK, Australia, France, Canada, Belgium, the Netherlands and Sweden. Of the 16 persons with available data, we noted that 10 were still single and 3 had children. Most of them worked and lived on their own. Many of them give con-

ferences, participate in meetings on the topic and develop experiences in autistic self-advocacy (see table 1). Our analysis illustrates the way in which the 'voice' of the autistic people has evolved in the last 2 decades. The first testimonies are personal accounts vouching for the credibility of telling their stories. Then, books and different writings went as far as challenging the authority of professionals [23, 24]. G. Bernot, S. Bonnot-Briey, M. Dawson, J. Lee O'Neill, S. Shore, J. Sinclair and L.H. Willey all supported the idea that autism is a different way of being rather than a disease to be eradicated. M. Dawson and J. Sinclair have been standing up for the rights of autistic persons, against discrimination and the catastrophic general representation of autism [23].

All of them described remaining impairments as adults: social impairment, withdrawal, difficulties in grasping emotions and understanding implicit rules and social conventions, as well as problems with generalization and poor adaptation to change. They mentioned peculiar perceptions and difficulties in the processing of sensory information with occasional overload and problems in processing information from more than 1 modality (sensory integrative dysfunction), as well as hypo- and hypersensitivity and sometimes the need for body pressure.

Some of them pointed out their difficulties in understanding what is being said and noted how they take language literally. Edgar Schneider (2003) explained:

I take things totally in a literal manner. I have no way of knowing when someone is serious or is merely 'kidding or teasing'. (p. 25)

Repetitive/limited interests and difficulties in the language domain are mentioned by 6 and 5 of them, respectively, and 3 had impairments in the motor domain described as lateralization difficulties, dyspraxia and coordination impairment. Many biographies mentioned gullibility. For Jim Sinclair (1992):

What my autism does to me is to make me vulnerable to being abused, and this has happened to me all my life. (p. 2)

Regarding the diagnosis of ASD, it was given by professionals, generally psychiatrists. Six among 19 had received this diagnosis during childhood before the age of 7. Five had a speech delay (S. Barron, J. Bouissac, F. Grandin, A. Carpenter, S. Shore) and J. Lee O'Neill is still mute. Even though most of the adults included in our study are considered now as high-functioning, many of them exhibited severe impairments when they were young. Those whose diagnosis was established when they were adults

reported having received previous diagnoses of either being mentally retarded, exceptionally gifted, emotionally disturbed or having nervous breakdowns, attention deficit disorders, eating disorders, borderline personality disorders or schizophrenia. They insisted on the positive consequences of the ASD diagnostic implications: a better understanding of themselves, a better quality of life and self-acceptance, a wish to read and express themselves on autism. Thus, Donna Williams decided to write her biography 2 years after discovering she was autistic. She considered her narrative as being a key moment in her self-construction. Wendy Lawson and Edgar Schneider felt relieved not to be schizophrenic [25].

Self-Reported Skills, Unusual Sensory-Perceptual Experiences, Cognitive and Emotional Functioning

A majority reported to have exceptional abilities in 1 or several specific domains including music, the animal world, mathematics, reading, memory, meteorology, computer science or foreign languages. The unusual sensory-perceptual experiences were the most frequently reported with hypo- and/or hypersensitivity, as well as sensory integrative dysfunction. Auditory hypersensitivity or hyperacusis may manifest themselves by an intense dislike or a painful response to certain types of noise, as already described [26, 27]. Many authors reported that they avoided being touched, disliked wearing certain clothes and sometimes abhorred washing, brushing and cutting their hair. Toothbrushing may also be painful. Certain foods are avoided depending on their taste, color or texture. Visual sensibility to bright lights is also described. Hypersensibility may be accompanied by hyposensibility such as a high threshold for pain and an apparent insensitivity. While some of them may be hypersensitive to some sounds, they may appear to be deaf to others.

Temple Grandin [28] explained:

My hearing is like having a sound amplifier set on maximum loudness. My ears are like a microphone that picks up and amplifies sound. I have two choices: 1) turn my ears on and get deluged with sound or 2) shut my ears off [...] I can't modulate incoming auditory stimulation. I discovered that I could shut out painful sounds by engaging in rhythmic stereotypical autistic behavior. (p. 1)

For Liane Holliday Willey (1999):

Bright lights, mid-day sun, reflected lights, strobe lights, flickering lights, fluorescent lights; each seemed to sear my eyes. Together, the sharp sounds and the bright lights were more than enough to overload my senses. (p. 26)

Gunilla Gerland (1997) reported:

My teeth were very sensitive and inside my mouth the consistency of some foods could be unpleasant, giving me a horrible feeling all over. (p. 15)

Temple Grandin and Stéfany Bonnot-Briey mentioned that at puberty, they were more anxious, nervous and had severe problems with sensitivity to touch and sound, as well as stomachaches and headaches for Stéfany Bonnot-Briey [29].

Concerning cognitive functioning, Edgar Schneider and others mentioned an acute ability to distinguish similarities from differences. A detail-focused processing style was precisely analyzed by Van Dalen [30], who described, for example, the successive steps he needs to reach the functional concept of a hammer. First, he perceives details, which are then combined into a coherent whole, which leads to the association with the label 'hammer'. Finally, he can understand the functional meaning of the hammer (a tool to use in carpentry). Difficulties in generalizing were mentioned by several autistic persons. Liane Holliday Willey (1999) stressed her inability to generalize information to specific situations:

I approach each new obstacle we come to as if I have never met anything like it before. (p. 102)

Distorted perception of time was reported by Van Dalen, D. Williams, T. Grandin, J. O'Neill and G. Bernot. Donna Williams (1992) described her strategy to compensate the impression of a world too fast for her:

One of these ways of making things seem to slow down was to blink or to turn the lights on and off really fast. (p. 78)

Finally, regarding emotional regulation, 6 subjects reported core impairments related to this domain. They described themselves as having an emotional deficit or an exaggerated emotional reactivity. Edgar Schneider (1999) explained:

I am an emotional idiot ... I have an important component of the human psyche missing: the ability to connect emotionally with other human beings [...] It is not that I am totally unfeeling, but that I just cannot read other people's signal. (pp. 25–26)

And later:

I seem to have compensated for my emotional deficit by developing my intellectual and aesthetic sensibilities. (p. 46)

In most writings, we found illustrations of emotional problems during childhood and/or adulthood.

Discussion

Perceptual Experience, Cognitive Functioning and Emotional Reactivity of Persons with ASD: Comparison of Self-Reports with Experimental Data

Despite individual variations between autistic persons in the range and severity of sensory idiosyncrasies, they are nevertheless described in most of the accounts as central to the autistic experiences including examples from sound, vision, taste, smell, proprioception, and kinesthetic stimulation of sensory distortions, sensory overload, synesthesia and difficulties in processing information from more than 1 modality concurrently. Sensory-perceptual idiosyncrasies and difficulties in processing information were portrayed as contributing to high levels of distress, fear and anxiety, but also as a source of pleasure. Fascination with certain patterns, lights, smells, movements and engaging in sensory stereotypes were sources of interest and pleasure. Jones et al. [15] corroborated turbulent as well as enjoyable sensory-perceptual experiences.

The reports of sensory peculiarities by parents of infants with autism, clinical observations, retrospective video observations as well as psychological research literature confirmed that unusual sensory responses are present in a majority of autistic persons. As early as 1964, Hutt et al. [31] proposed a theory of the causes of atypical behaviors of persons with autism based on the observations of hypo- or hyperarousal, and experimental studies showed evidence of atypical responses to sensory stimuli in autistic subjects. Indeed, unusual sensory responses were included as one of the diagnostic criteria for an assessment of autism in DSM-III (1980), although omitted in later formulations [14].

Using parental reports, Ornitz et al. [32] found that before the age of 6 years, 70% of autistic children showed either altered sensory sensitivities or nonresponsiveness in the auditory, visual, tactile or vestibular modalities. Twenty years later, Kientz and Dunn [33] demonstrated that the sensory profile questionnaire completed by parents differentiated the sensory processing skills of children with autism from those without autism. Atypical sensory-perceptual behaviors appear to persist throughout the development of individuals with autism [34] but have the potential to improve with age [27]. In 2006, Iarocci and McDonald [35] reviewed the research on sensory issues in autism.

Functional imaging and electrophysiologic literature strengthened the importance of atypical sensory experiences of people with ASD. By using magnetic resonance imaging, Boddaert et al. [36] showed that adults and chil-

dren with autism have atypical cortical auditory processing when listening to speech-like sounds. Oram Cardy et al. [37] identified rapid temporal processing impairments in autism by using magnetoencephalography. By measuring average evoked potentials, Novick et al. [38] pointed out auditory defects in autism. Atypical color perception was studied by Ludlow et al. [39], who demonstrated the positive effect of colored overlays on reading ability in children with autism. Bertone et al. [40] confirmed that the peculiarities observed in autistic visual perception are contingent on the complexity of the neural network required to process a given type of visual stimulus. They suggested that atypical neural connectivity may account for both enhanced and decreased low-level information processing in autism.

The sensory-perceptual idiosyncrasies, along with impairments in emotional regulation, are described by the autistic persons who expressed themselves as contributing to their social and communication difficulties. Talay-Ongan and Wood [41] already argued that unusual sensory sensitivities evidenced in autism are likely to have repercussions on cognitive-linguistic and socioemotional outcomes. The personal accounts illustrate the strong association between perception, sense-making and communication. Even for verbal people with autism, sense-making is often fragmentary and literal [42]. The accounts illustrate also their emotional reactivity. Indeed, the studies of Jones et al. [43] and Ben Shalom et al. [44] paint a complex picture of the emotional lives of people with autism. Recently, Berthoz and Hill [45] confirmed the validity of using self-reports to assess emotion regulation abilities in adults with ASD.

The enhanced discrimination of differences and novelty mentioned by some of them was studied by Plaisted et al. [46]. De Clercq [47] detailed the over-selectivity which characterizes the perception style of autistic persons, previously described by Van Dalen [30]. On the one hand this specific style leads to difficulties in combining experiences into a meaningful whole, but on the other hand it facilitates special abilities [48]. As early as 1944, Kanner [4] observed that autistic children had difficulties in experiencing wholes, they gave their full attention to the constituent parts and this tendency to focus on details has been recognized by many clinicians since [49]. Evidence for this atypical perceptual functioning with focus on details and the processing of visuospatial information in a fragmented way was recently analyzed by Brian et al. [50], Mottron et al. [51], Brosnan et al. [52] and Schlooz et al. [49]. The recent studies of Gepner [53] focused on the visual motion processing associated with a distorted per-

ception of time reported by some persons with ASD who have difficulties in processing fast moving visual events and exhibit compensatory strategies aimed at slowing down the speed of movements, such as described by Donna Williams.

Autobiographical accounts provide a relevant source of information on the subjective sensory-perceptual experience of people with ASD, reinforced by several of the current psychological theories of autism. The weak central coherence theory stressed the impairment of the ability to integrate information across a variety of contexts for high-level meaning [54]. Temporal binding has been proposed as a key process involved in the perceptual as well as high-order deficits observed in autism [55]. According to the theory of mind, autism is the reflection of the inability to conjecture the mental states of others, or perceive their intentions, beliefs and desires. The capacity to interpret mental states is dependent on seeing, hearing and touching and is severely compromised by sensory processing aberrations [41]. Various theories exist which implicate unusual sensory processing as a core feature of autism.

Major Contribution of Autistic Persons' Experiences regarding the Current Psychiatric Nosography

Regarding the psychiatric nosography, the autistic persons' view concerning the core impairments is particularly interesting, although they did not comment or argue on it specifically (fig. 1).

Since the 1980s and the publication of DSM-III, psychiatric nosography has been based on consensual diagnostic criteria that are modified according to studies testing validity [56]. One major limitation of this approach, despite many benefits, is that external validity is better achieved when clinical criteria are associated with external description of behaviors or symptoms. Thus, in the field of autism, it is easier to achieve validity for symptoms such as 'no expressed speech' or 'stereotypies' than 'hypersensitivity to noises' or 'emotional regulation dysfunction' because dealing with intrapsychic experiences is more complex. As a consequence, psychiatric nosography has selected 3 major domains for diagnosis of ASD that can be assessed by external evaluation: deficits in social relationships, communication impairments, repetitive behaviors and restricted interests.

The current study based on first-hand accounts of persons with ASD shows that what has been selected as major signs by psychiatric nosography is regarded as a consequence of their atypical perceptions and emotional regulation problems by the autistic individuals who expressed themselves (fig. 1). Despite the non-representativeness of

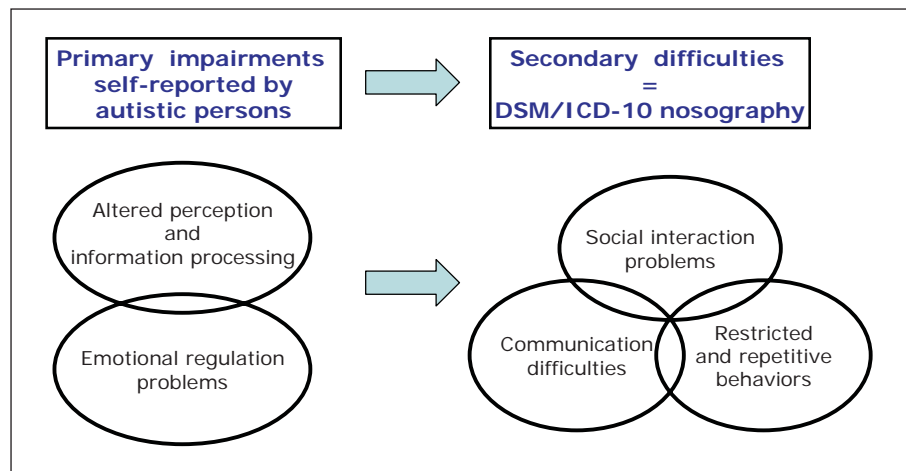


Fig. 1. Major contribution of autistic persons' experiences regarding the current psychiatric nosography.

the 20 accounts analyzed in our study, the results concerning atypical perceptions and emotional regulation problems have been strengthened by numerous clinical observations, parents' reports, imaging and electrophysiologic literature as well as cognitive science studies. We believe that our findings, along with all the results obtained until now, could be taken into account in the next classifications.

Conclusions

The current approach stresses the importance of the personal experiences of autistic persons to integrate theories into a larger vision of autism. Indeed, one of the major difficulties with a theory is the tendency to focus on 1 aspect and then generalize without keeping in mind the other components. Often, causes and consequences are not really distinguished. Our results show that autistic people who express themselves and who try to understand how they function have deficits in social relationships, communication impairments, repetitive behaviors and restricted interests derived from their unusual perceptual sensitivities and their special mode of thinking (detail-focused processing style) as well as their emotional regulation problems. These considerations deserve to be taken into account by professionals to better understand the behavior and needs of persons with autism and influence treatment programs. They could be most useful in establishing detailed evaluations so as to throw light on the causes of apparently erratic behaviors, and thus helping parents and caregivers to look after the autistic persons in an appropriate manner.

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Appendix

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