

AUTOBIOGRAPHICAL WRITINGS BY AUTISTIC PERSONS : A SYSTEMATIC STUDY

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Background

Different theories and scientific backgrounds have been used to approach the psychopathology of autism. However, to date, few studies have focused on the viewpoints of the autistic persons themselves despite many existing autobiographies. We failed to find any systematic study of this material although some comments on the most popular biographies by Temple Grandin and Donna Williams have been published.

Objectives

- (1) To collect published materials from persons with autism focused on their personal experiences
- (2) To systematically explore their viewpoints on autism

Methods

Adopting an anthropological approach, we analyzed 15 autobiographies by persons with autism or Asperger syndrome (AS) (8 ♂, 7 ♀ - 22 to 74 years old). 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. We systematically screened this material exploring several characteristics including biographic events, cognitive skills and interests. We also focused on unusual sensory perceptual experiences and their inside view of autism.

RESULTS

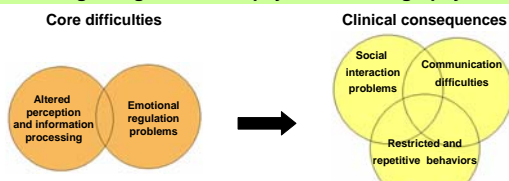
SOCIODEMOGRAPHIC CHARACTERISTICS AND CURRENT STATUS OF 15 AUTISTIC PERSONS

Author Country	Title, year	Sex	Birth	Current status	Diagnosis (Age)	Current activities	Remaining impairments as adult
Schneider Edgus US	<i>Discovering my autism</i> , 1999 <i>Living the good life with autism</i> , 2003	M	1932	Remarried 3 children	Nervous breakdown (46) Schizophrenia (68) AS (63)	Retired (computer sciences) Autism conferences	Difficulties in decoding emotions and social relationships, gullibility, lack of empathy, attention deficit disorder, literal understanding
Temple Grandin US	<i>Emergence: labeled autistic</i> , 1986 <i>Thinking in pictures and other reports from my life with autism</i> , 1995	F	1947	Single	Autism (5)	Professor of zoology Autism conferences	Difficulties in decoding emotions and social relationships, obsessions, phonological problems, sensory integrative dysfunction, memory impairments, lateralization difficulties, need of body pressure, literal understanding, anxiety for changes
Newport Jerry US	<i>Your life is not a label</i> , 2001	M	1948	Married	AS (47)	Writer on ASD subjects	Social impairment, avoids eye contact
Lawson Wendy UK	<i>Life behind glass. A personal account of autism spectrum</i> , 1998	F	1952	Divorced 4 children	Schizophrenia (18) AS (42)	Autism conferences	Social impairment, obsessions and compulsive behaviors, unable to identify, understand and express his emotions, terror of change and separation, literal understanding, difficulties in generalizing
Carpenter Anne US	<i>High-functioning individuals with autism</i> (Ed. Schopler E. Mesibov GB), 1992	F	1957	-	Congenital rubella Autism (5/30) Mentally retarded	Librarian for the Autism Society of Michigan	Poor social skills, mannerisms. Fixations, repetitive conversations on the same topics. Lack of concentration. Difficulties in generalizing from one situation to another
Wiley Laune Holiday US	<i>Pretending to be normal. Living with Asperger's syndrome</i> , 1999 <i>Asperger syndrome in the family. Redefining normal</i> , 2001	F	1959	Married 3 children	Exceptional child (3) AS (40)	Psychologist Autism conferences	Social impairment, sensory integrative dysfunction, bilateral coordination problems, auditory discrimination, echolalia, rigid thinking, obsessions, literal understanding, semantic pragmatic disorder
Barron Sean US	<i>There's a boy in here</i> , 1992	M	1961	Single	Autism (4)	Social worker for elderly people	Social impairment, lack of understanding implicit rules and social conventions, dyspraxia
Shore Stephen US	<i>Beyond the wall. Personal experiences with autism and Asperger syndrome</i> , 2001	M	1961	Married	Autistic characteristics (2)	PhD in special education Autism conferences	Hypersensitivity (sounds, skin contact), sensory integrative dysfunction, odd prosody, impaired emotional expression, echolalia, echopraxia, echomimesis. Lack of understanding social conventions
Williams Donna Australia	<i>Nobody nowhere</i> , 1992 <i>Somebody somewhere</i> , 1994 <i>An inside-out approach</i> , 1996	F	1963	Married	HF autism (26)	Writer Artist Autism conferences	Sensory integrative dysfunction, hypersensitivity (sounds, skin contact). Difficulties in decoding people's intentions and emotions, as well as social relationships, naively. Cannot generalize a rule.
Gerland Gunilla Sweden	<i>A real person. Life on the outside</i> , 1996	F	1963	Single	HF autism (29)	Autism professionals Autism conferences	Social impairment, lack of empathy, hypersensitivity (noise, skin contact), sensory integrative dysfunction, literal understanding. Poor flexibility. No stress tolerance. Gullibility.
McKean Thomas US	<i>Soon will come the light: a view from inside the autism puzzle</i> , 1994	M	1965	Single	PDD-NOS Autism (14)	Post, musician, writer, autism conferences, ASA member	Hypersensitivity (gustative, tactile, visual, hearing), unable to speak when frightened, hear inner voices, lack of imagination, skin contact, lack of libido and appetite, immobility, feels continuously low-intensity pain (pressure cravings), anxiety, insomnia.
Stinchir Jim US	<i>Bridging the gap: an inside-out view of autism. Don't mourn for us</i> , 1993	M	1965	-	Autism (-6)	Co-founded ANI and service dogs for autistic people	Social impairment, hypersensitivity. Auditory and visual processing difficulties
Segar Marc UK	<i>The battles of the autistic thinker</i> , 1997 <i>A survival guide for people with Asperger syndrome</i> , 1997	M	1974	Single Dead in 1997	Autism (7)	Children's entertainer Autism consulting	Social impairment, no understanding of implicit rules and social conventions. Difficulties in planning tasks.
Lee O'Neil Jasmine US	<i>Through the eyes of aliens. A book about autistic people</i> , 1999	F	-	-	Autism (26)	Writer	Hyperemotional, hypersensitivity, self-stimulatory behaviors, obsessions, speaks like a child, literal understanding. Different perception of time.
Bouissac Jeffrey France	<i>Qui j'aurai été</i> , 2002 <i>Diary of an autistic teenager</i>	M	1980	Single	Autism (15)	Open university courses	Soliloquies, limited interests, sensory issues, feelings of anxiety especially when the weather changes, rituals, withdrawal to his inner world, phobia obsessions, difficulties in grasping emotions.

AN INSIDE VIEW OF AUTISM

Cognitive skills/interests	Sensory Sensitivities and Emotional functioning	Consequences of autism discovery	Autism definition	Etiological theories	Hopes and claims
Highly developed learning skills both intellectual and artistic, diversified interests, music love. "Walking encyclopedia"	Tactile hypersensitivity and high threshold for pain. Emotional deficit. Wide visual field. Acute ability to distinguish similarities from differences.	Felt liberated, better quality of life and self acceptance, able to explain his functioning mode to the others	Emotional deficit. For him, some autistic characteristics can be viewed as insignificant eccentricities. Yet other behaviors disturb non autistic people by questioning their normative values	Any element that may interfere with the nervous system development. Thinks that a whopping cough (3-4) would have triggered his autistic behaviors (infectio-caused neurological impact)	Hopes that his books will help teachers, educators and parents to understand better the functioning modes of autistic children, and make fewer mistakes
"Visual thought, ability to abstract, particular interest for restraining devices. Born with the ability to live in the animal world, completely understanding their environment"	Hypersensitivity to noises, odors, movements, twisting. Exaggerated emotional reactivity. Sensory integrative dysfunction, relieved thanks to a restraining device	Diagnosis at the age of 3	Developmental disorder of the nervous system, defects in the systems processing sensory data	Neurobiological model of autism, possible biochemical defects, likely involvement of genetic factors	Hopes to provide peer guidance by a scientific approach. Approves of an early multidisciplinary approach within a tailored educational program. Links autism to creativity. "A world with no autistic individuals would be conventional, boring and deprived of any original thinking"
Excellent visual memory. Could read at two. Could play music after hearing it once only, at five. Ability to do mental, numerical, calculations at seven. Interest for politics, sports, music and nature	Sensory overload. Sensory integrative dysfunction	Went looking for others like him. Organized a support group	AS is an unusual or bewildering condition not a disability. He thought of himself as "differently able"	-	Never felt that AS was a disability even when he lacked a name for it. Thinks he is able and incompetent in a skewed, very different way.
Unquestionable thirst for learning. Good potential in English. Real gift for swimming	Highly developed sensory autistics, hypersensitivity to noises generating confusion (sensory overload). Emotional reactivity	Relieved not to be schizophrenic, better understanding of herself, life enjoyment	Alters the individual and her/his vision and understanding of the world	Nervous system disorder, possible genetic origin	Wants to share her understanding of autism with the others, so that AS should be known and diagnosed at an early stage. Wants to show to the world that she is not stupid as she considered herself for years. Wishes to establish genuine relationships and wants to be like the others
Excellent verbal and intellectual skills	Hypersensitive to light. Could not make eye contact. Vulnerability	"Diagnosis was to be the force that would change my life". Over the ensuing months, became calmer and happier. Could find ways to eliminate at least some of the odd and socially unappealing behaviors	"Monstrous problem". Disease.	Neurological origin	Hopes that recent research in autism makes society more willing to meet the needs of this particular population
Could read at the age of 3. Diversified interests: languages, the cinema, Far West stories, pottery, architectural design	Hypersensitivity (smells, touch, noises, bright light, movements), sensory integrative dysfunction, sensory overload, throws temper tantrums quite often, bilateral coordination problems	Got reconciled with the autistic part of herself, assumes herself better, and does not hesitate to express herself when she is disturbed in a public place (noises, smells, lights)	Autism is a very broad zone encompassing skills and deficiencies with many fluctuations and differences. Having AS means that you are different but not handicapped	Neurological origin	"Autistic people should not be expected to become the accurate replicas of 'normal' individuals". Importance of the sensory integration therapy. Importance to train people to understand, accept and support AS better. Positive outlook on AS: eccentric, creative, inventive, geniuses, socially indispensible
Interest for mathematics, astronomy. At the age of 15 learnt the dictionary by heart in 8 weeks	Sensory hypo and hyper sensitivity. Partial perception of his body. Hearing discrimination problems. Self-awareness at age 14. When watching a film, the details catch his attention	Medical and therapeutic interventions. Sean did not understand why he had to go to the doctor since he did not feel sick	Autism was like a jail preventing him from establishing social interaction	-	Explains his mode of functioning and evolution. He knows he will not be cured but he feels much better
Special interest for technical devices (bicycles, watches, locks, computers, airplanes, electricity...) and weather, astronomy, chemistry, psychology, shiatsu, yoga or playing the trombone, the trumpet	Hypersensitivity (hearing, touch, olfaction). Sensory integrative dysfunction. Detail-focused processing vision	-	AS is a "way of being" rather than a "disorder". It's another order	Considers autistic behaviors as the side effects of the brain protecting itself from an overload of sensations	Societal constructs relating to how others compare those with autism and AS to the rest of society play a heavy role. Thus, he expects an increased mutual understanding among those with autism and society at large. Uses his personal experience and research to help the others on the autism spectrum develop their capacities
Particular skills for music, painting, sculpture, writing and good memory	Sensory integrative dysfunction, tactile, hearing and visual hypersensitivity. Emotional hypersensitivity. Perceives parts of the body as foreign. Cannot see other people as wholes	Two years after her autism discovery, she wrote her first book which allowed her to reconstruct herself	Having trouble with connections, tolerance and control. Autism is not a mental disease	Biological dysfunction due to brain developmental problems. Dietary problems may cause or aggravate autism	Rejects the psychiatric nosography, the idea of mental retardation for autistic persons, and the term "autism" itself. "The eradication of symptoms may often be a relief to parents and professionals but it is like seeking to cure epilepsy by teaching people how to act normal during an attack"
Photographic memory. Self-taught at 5 (writing and reading). Knows all his children's books by heart. Good at drawing, painting and operating a computer	Hypo sensitivity (physical pain, some sounds) and hypersensitivity (noise, teeth, milk, touch, hair, food). Synesthesia. Hyper laxy. Motor system clumsy. Occasionally, loss sense of perspective. Two-dimensional vision. Difficulties for evaluating speeds and distances.	She read on the subject extensively. Understands herself better. Thinks that her autism protected herself from her dysfunctional family	Handicap	Biological origin	Active in promoting an understanding of autism and the deficit of autistic people
Gifted for music. Exceptional skills in computers, sculpture, writing system and technical design	His five senses are dysfunctional and not always reliable. Sensory overload. Emotional deficit	Invests all his energy in a quest of autism knowledge. Activism for the rights and deficit of autistic people	A multi-sensory disorder	Permanent fear and inadequate behaviors due to a sensory information processing dysfunction and a difficulty to communicate	Proposes to understand autism better, and advocates a more active and demanding attitude from autistic persons. Would appreciate to be a little more normal without necessarily being cured. Feels lonely and longs for a friendly relationship with a girl
-	Sensory overload. Oversensitive (hearing and vision) Poor visual processing. Synesthesia. Perceptual problems affect his understanding	-	"Being autistic means being different. It is a way of being which colors every experience, sensation, perception, thought, emotion". Autistic people have the same needs for relationships as other people	Connections between different sensory modes or different items of stored data may be atypical	"I have no wish to be cured of being myself". "Being autistic does not mean being mentally retarded, emotionally disturbed or being unable to learn... The role of professionals should be to help people use their natural processes to learn and grow. Honest and direct communication is better than therapy"
Photographic memory, gifted for music, interests: foreign languages, science, history, computer science	Synesthesia	-	Autistic people are not aware of the many un-written rules "they have to understand scientifically what non-autistic people already understand instinctively"	Autism is caused by various biochemical processes which alter the brain development	His objective was to make clear the implicit rules for helping autistic people and upgrading their quality of life. "Autistic persons have to understand in a scientific way what the others understand in an intuitive way"
Creative writing, art and music. Visual thought	Hyper-emotional and hyper-sensitive	-	Autism is not an illness. It refers to a special kind of mind, a special type of personality	In autism, there is a specific brain dysfunction, which influences certain ways of thinking, alters emotions and sensory experiences	People who are not autistic lead very different lives from people who are autistic. In her book, she explains how autism can be seen as a truly beautiful event
Interests: meteorology, radio frequencies, the human body and health, music, disaster movie and documentaries	Hypersensitivity (odors). Emotional reactivity	Wants to be cured and have a normal life	Handicap and differences	Genetically based. Mentions an intense tropical fever which lasted a month when he was 9 months old	Learning English to go to Canada, having a job, getting married and having children. To be cured and not considered as insane

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



Discussion

Autobiographies written by autistic persons provide an inside view of autism which can be useful on cognitive theory and research, clinical practices, and teaching autism. Our approach allowed us to show that what has been selected as major signs by psychiatric nosographies is regarded as a consequence of their **atypical perceptions, information processing and emotional regulation problems** by autistic persons who have expressed themselves. These results have been strengthened by numerous clinical observations, parent's reports, imaging and electrophysiology literature, as well as cognitive science studies. We suggest that our findings, along with all the results obtained until now, could be taken into account in the next psychiatric classifications.