

Bosch's Cases: a 40 years Follow-up of Patients with Infantile Autism and Asperger Syndrome

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Abstract

Only a handful of longitudinal case reports on autism spectrum disorders exist in the literature. In this study, we present the follow-up data on two subjects with infantile autism and one with Asperger syndrome over 40 years after initial diagnosis. Their childhood phenomenology had been described in detail in a historic monograph by Gerhard Bosch (1962, 1970). The trajectories of his three former patients were consistent with more recent larger scale empirical studies on outcome in autism and related disorders. While the two cases with core autism had poor outcomes compared to the person with Asperger syndrome, all three of them showed a highly stable symptomatology from childhood into adulthood. The study confirms the stability and validity of the diagnosis of autism over the years (German J Psychiatry 2004; 7:10-13).

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Introduction

Infantile autism, first described by Leo Kanner (1943), and other pervasive developmental disorders (PDD) the individual outcome in adulthood can vary strongly depending on factors like severity and comorbidity as well as the availability of adequate intervention, education and general support. However, only non-verbal intelligence and language skills in preschool years have empirically proven robust predictive value (Gillberg & Steffenburg, 1987). A low level of expressive speech and profound mental retardation is regularly accompanied by very limited social-communicative and adaptive functioning in later life. Even though single subjects with autism can experience considerable symptom improvement and psychosocial adaptation during their development, the vast majority of cases require at least some supervision, care or attention throughout life. Howlin and Goode (1998) reviewing 17 outcome studies undertaken between 1956 and 1995 with samples sizes between 14 and 126 individuals conclude that despite behavioral improvements and remarkable exceptions most of affected subjects had poor outcomes in adulthood, with low employment ra-

tes and a substantial subgroup being dependent on their families or living in institutions. To a lesser degree, the same is also true for people with high-functioning autism and Asperger syndrome (Larsen & Mouridsen, 1997).

The work of Gerhard Bosch (1962, 1970)

Between 1951 and 1962 Gerhard Bosch worked as junior and senior psychiatrist at the department of child and adolescent psychiatry at Frankfurt University, Germany. During this period, he discovered his interest in autism and associated disorders. Later he published five detailed casuistries of individuals affected by a PDD in a monograph (Bosch, 1962) and thus became one of the first scientists to establish research on autism in Germany. Because of the attention his monograph also raised outside the German speaking audience, an English translation was made available eight years later (Bosch, 1970). Still his vignettes are frequently quoted in the contemporary literature (e.g. Attwood, 1998; Lord & Bailey, 2002).

In this article, we briefly report the results of a follow-up examination of three of these patients (Hans R., Karl B., Ri-

chard L.), two with autism and one with Asperger syndrome. In all cases the interval between the first clinical referral and the catamnesis was more than 40 years. Despite of accounts by Kanner himself (1949, 1973), comparable longitudinal case reports have very rarely been published.

Case reports

Case 1: Autism

Born 1942, Hans R. was first admitted to the clinic in Frankfurt aged 10;3 years. After six weeks as an in-patient he was regularly seen as an outpatient until the age of 16;3 years. The parents had not noticed anything abnormal until his third year. Then, when visiting kindergarten, he was unable to adjust, withdrew and did not pay attention to teachers or joined in games. Likewise, he did not socialize outside kindergarten. His problems continued at school. During the lessons he frequently stood up, while the teacher was lecturing, walked around and talked to himself. He also occasionally had scuffles with classmates, because without obviously being aware what he was doing, he could grab other's belongings or push children out of his way. When he was seen in Frankfurt by Bosch at the age of ten, he made a fresh and healthy impression, carefully dressed and well looked after. He had an unusual gaze, was closely tied to his parents and had not acquired age appropriate daily living skills. Attempts to influence his behavior and routines were always encountered by massive resistance. When left alone, he talked away in a lilting voice or sang tunes and texts that did not make sense. He never used language for social communication, and his speech contained many oddities, for instance pronominal reversal and neologism. Moreover, he seemed to have major difficulties to grasp what others were saying. He also exhibited stereotyped movements, like skipping around humming and waving his arms in the air. He had a particular interest in round and rotating objects and kept a collection of wheels. To summarize his behavior Hans R. was given a diagnosis of primary, infantile autism. According to the observations in the following years his behavior did not change remarkably until aged 16.

The follow-up examination took place in September 2001, in a long-term psychiatric residential institution, where Hans R. had spent the last 25 years of his life. According to the files and the staff reports, his behavior had been stable during this time. Before moving to the institution he had essentially lived in his parents home. Aged 58 years, Hans R. looked neat, childlike and fragile. At contact he hardly took notice, looked down, was restless and left off after a short while. In his daily living he was largely depending on the help of the staff, but was able to take care of his personal hygiene. He was not orientated to location and refused to leave the building, for instance to participate in excursions. Hans R. preferred staying in his room, strictly following his daily idiosyncratic routines, like drinking yellow sparkling lemonade at 10.20 a.m. and taking a nap of 15 minutes at exactly 1 p.m.

He frequently sits on a chair rocking and repeating the same phrases over and over again (e.g. 'the dentist shall not drill', 'I don't want to eat beetles here'). Changes in his schedule always led to distress. In 1993, when the residence was renovated, he experienced a severe nervous breakdown and fell into a catatonic stupor for several weeks. Hans R. does not have any social contacts, despite some ritualized verbal interaction with the staff, from whom he frequently demands various calming comments (e.g. 'everything is fine', 'you're a good boy'). Otherwise he avoids people and social events in the institution, unless there is cake to eat. He is very discriminating concerning food and gets easily irritated if the meals do not fit him. Regarding meat, he will only eat meat balls and chicken.

Case 2: Autism

Karl B., born 1950, was first admitted to the children's ward at 5;2 years and stayed for five months. First words appeared slightly late when he was two years old. He then only started echoing what others had said, and never used 'I', but 'he' or his first name do reference to himself. He had few adaptive skills, avoided eye contact, was restless and fearful, hard to conduct and had no interest in other people or his surrounding in general. Reaction to name was poor, he refused a broad spectrum of food, excessively played with his genitals and showed aggressive behavior and self-injury when caused to do things or approached by other children. In addition, rocking his body, finger mannerisms, sensory interests in the shape of surfaces and repetitive play (stabling wood blocks) characterized his behavior. On the basis of clinical observation and anamnesis Karl B. was given a diagnosis of infantile autism.

Karl B.'s follow-up was carried out in a closed long-term institution for mentally retarded individuals north of Frankfurt in June 2001, accompanied by his mother. Now aged 51 years, he had lived in comparable homes since his sixth year of life. He looked unhealthy, younger than his age, had a tall, gawky habitus and spend most of his days crouched on a couch looking television and masturbating. Otherwise he could be very overactive, walking back and forth aisles rocking his body. He still had temper tantrums and impulsive, unpredictable aggressive behavior, but to a lesser degree than in younger age, and would rather just try to escape the situation when annoyed. He had acquired a limited range of adaptive skills and partly participated in the routines of the home (e.g. taking his meals together with other patients). However, he never joined group activities and preferred to be on his own. He showed some ritualized verbal communication with the staff, which had decreased in the last years. Recently, he had started to communicate by using other's bodies (e.g. takes another person's hand to point or turning a door knob) or just by making sounds (e.g. hissing, rumbling). He exhibited compulsive patterns, for instance he would only drink, if all doors were closed, two glasses filled and the staff carried their keys visible. Like in childhood, he was extremely selective with regard to food and would not tolerate anything else but sliced cold meat on his sandwich.

Case 3: Asperger Syndrome

Richard L., born 1932, was first referred to the clinic aged 22, due to an increasing tendency for epileptic attacks since puberty. In addition, there were concerns because of self-injurious behavior (pulling out hair, beating head). He stayed at the clinic some days for observation and was then seen as an out-patient over six years. His parents described him as always been peculiar. Language development was on time, but speech remained faulty until the age of five. From early on Richard L. had very intense and absorbing interests, particularly in numbers, cans and plates. He also enjoyed building complex structures using wood blocks and showed a passion for music. At primary school he even started composing under his mother's guidance and it became clear that he had an absolute pitch. Aside from his talents he remained incapable of performing even the simplest daily tasks without assistance. Aged six years he started to create an elaborated inner world of fantasy and spirituality he called 'Resteten', a perfect world on which he worked in his mind for several years. In general, he had remarkably little contact with other people. At grammar school he met a boy with whom he started to play music and talked about mathematics and paintings. Although they had done things together they hardly ever had exchanged personal thoughts or fantasized about the future. At the time of admission at the clinic in Frankfurt Richard L. had begun to study physics at university and moved from his parent's house. He lived alone and was looked after by a landlady. Richard L. showed an interest in architecture and nature, which he also expressed by trying to capture it in drawings. He would read animal stories, text and non-fiction books, but avoided novels, for he felt they were rubbish to him. While he talked to other students about factual issues he had no contact with them outside the classroom. However, he had formed an attachment to a woman. They got on very well in many respects, but had decided not to marry, because neither believed to have sufficient ability to cope with life. At his stay in the clinic Richard L. always showed an extraordinary patience and punctuality. While talking to him he would stare like a child and made the impression of a lost, naive and helpless young man. Hans R. was given a diagnosis of Asperger syndrome.

The follow-up examination was carried out in Richard L.'s home in southern Germany in April 2001. He, now aged 69 years, lived together with his wife in a quite shabby and chaotic rather hut-like house in a suburban area. Richard L. made a gaunt, stiff and clumsy impression. He acted friendly but often socially awkward or inappropriate (no greeting, not offering drink, food or a seat, forting loud). He had taken the diploma degree in physics in 1961 and had worked at an institute for plasma-physics until he retired 1997. In 1962 he married the acquaintance from his time at university, after having ensured himself that she could 'prepare meat'. From hindsight, his wife, a retired computer scientist, disappointedly characterizes the marriage as not having taken place, and that she just overtook a mother role. She complained that Richard L. had been impractical throughout and always failed when attempting to do anything in the household. The couple had undertaken a lot of traveling together in former

years. Aside from journeys in Germany they had visited Egypt, Israel, Greece, Spain and Tunisia.

Richard L. described himself as 'socially handicapped' and as a 'cultural ruminant'. Even though he had tried to have social contacts outside his work he never managed or could see the sense in it. Also all psychotherapy and medication he tried and was given did not help. He occasionally worked as an organist in a church nearby, where the 'social things were taken care of for him'. In direct social interaction he revealed a monologues flood of words, hard to disrupt and accompanied by exaggerated gestures. He repeatedly revolved around certain topics, especially 'Resteten', playing the organ, painting, nature, transcendence and visions. To illustrate his thoughts he often used the story of 'Heidi' by Johanna Spyri, that he had read about 15 times. In contrast to real individuals he showed a credible empathy for figures in fictions. While talking, he made a pensive and world-weary impression, but always with sufficient critical distance to his suggestions. With one exception he had not experienced epileptic attacks for 30 years. Also his self-injuries had disappeared, because he realized that he also harmed the organist and artist in him with it. However, he only described the situation as 'ceasefire after a temporary civil war in the cell state Richard L.'

Discussion

With these three case reports, we intended to provide true life longitudinal histories of people with an autism spectrum disorder. Three individuals who had been precisely described by Bosch (1962, 1970) four decades ago were retrieved and reexamined. In consideration of the contemporary view on outcome in core autism and Asperger syndrome the subjects examined here seem to be quite prototypic. Hans R. and Karl B., two clear cases of autistic disorder with functional speech abnormalities in childhood and probably borderline or retarded intellectual abilities, show a strikingly steady autistic phenomenology over life span with a very low outcome and high dependence on support. Richard L., diagnosed Asperger syndrome, who due to his language abnormalities until the age of five and DSM-IV/ICD-10 criteria today might be classified as suffering from (high-functioning) autism, reached a good outcome, being married and living independently. However, he as well showed a relatively high stability and consistency of autistic symptoms. In summary, this historical report again documents that autism spectrum disorders are qualitatively chronic conditions. Furthermore, despite several major changes in the classification of autism in ICD and DSM since Bosch's work, the study demonstrates the (prognostic) validity of the diagnosis over time.

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