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Autism in community pre-schoolers: Developmental profiles

Anne-Katrin Kantzer [a,b,*], Elisabeth Fernell [a,c], Christopher Gillberg [a], Carmela Miniscalco [a]

[a] Gillberg Neuropsychiatry Centre, Sahlgrenska Academy, University of Gothenburg, Sweden
[b] Department of Child and Adolescent Psychiatry, NU Hospital Organization, Trollhättan/Uddevalla, Sweden
[c] Unit of Neurodevelopmental Disorders, Skaraborg Hospital, Mariestad and FoU-Center, Skövde, Sweden

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ABSTRACT

Autism is often a complex developmental disorder. The aim of the present study was to describe the developmental characteristics of 129 1–4-year-old children (102 boys, 27 girls) referred for clinical assessment (mean age 2.9 years) due to suspicion of autism spectrum disorder (ASD) after community screening at Child Health Care centers. All children were clinically assessed at the Child Neuropsychiatry Clinic (CNC) in Gothenburg by a research team (neurodevelopmental examination, structured interviews and general cognitive and language examinations). Of the 129 children, 100 met diagnostic criteria for ASD (69 with autistic disorder, and 31 with atypical autism/pervasive developmental disorder-not otherwise specified). The remaining 29 children had a variety of developmental disorders, most often attention-deficit/hyperactivity disorder (ADHD), language disorder, borderline intellectual functioning, and intellectual developmental disorder (IDD) with ($n = 25$) or without ($n = 4$) autistic traits (AT). IDD was found in 36% of the 100 children with ASD, and in 4% of the 25 children with AT. Of the children with ASD, 56% had language disorder with no or just a few words at the initial assessment at the CNC, many of whom in combination with IDD. Hyperactivity was found in 37% of those with ASD and in 40% of those with AT. Epilepsy was found in 6% of the total group and in 7% of those with a diagnosis of ASD. Of the latter group 11% had a history of regression, while none of the AT cases had a similar background. When results were compared with a non-screened preschool ASD group of 208 children, referred for ASD intervention at a mean age of 3.4 years, very similar developmental profiles were seen. In conclusion, early community ASD screening appears to systematically identify those children who are in need of intervention and follow-up.

1. Introduction

Autism spectrum disorder (ASD), with its core symptoms in the areas of social interaction, communication and limited interests in activities or play, is also still referred to as pervasive developmental disorder (PDD). ASD comprises a wide variety of clinical phenotypes, presenting during the child's first years of life. As is the case with other developmental disorders, ASD occurs with many other conditions (Nazeer & Ghaziuddin, 2012) and there is usually either general cognitive

* Corresponding author at: Gillberg Neuropsychiatry Centre, Sahlgrenska Academy, University of Gothenburg, Kungsgatan 12, 411 19 Gothenburg, Sweden. Tel.: +46 31 342 5970.
E-mail address: anne-katrin.kantzer@vgregion.se (A.-K. Kantzer).

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dysfunction, language delay, hyper- or hypoactivity, attention problems, or deviant motor development. These developmental problems are now frequently referred to as ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) (Gillberg, 2010). In order to understand the heterogeneity of ASD in general, and the needs of individual children in particular, it is important to increase knowledge about these children's early developmental profiles and to follow their development and trajectory over time.

Many recent studies underline the importance of early identification and of tailoring individual intervention programs to improve outcomes in ASD (Dawson & Gernsbacher, 2010; Eikeseth, 2009; Magiati, Charman, & Howlin, 2007). The American Academy of Pediatrics (AAP) recommended in 2001 and 2006 that developmental surveillance should be carried out at every visit at Child Health Care (CHC) centers and that any concerns raised during surveillance should be addressed promptly with standardized developmental screening tests (Johnson & Myers, 2007). In addition, the AAP recommends that screening tests should be administered regularly at the 9-, 18-, and 24- or 30-month visits.

In Sweden, children are followed at CHC centers during their first five years of life. The routine follow-up includes developmental surveillance and screening at certain key-ages in order to see if the children meet developmental milestones. About 95–99% of the children in the Gothenburg area, Sweden, participate in the surveillance program (Arvidsson, Holmberg, Reuter, & Strömbom, 2010). One of these general national screenings mainly focuses on language of 2.5-year-old children. In 2008, a new screening program focusing on both language/communication, and on ASD, was introduced at the CHC centers in the Gothenburg area (Nygren, Sandberg, et al., 2012). The screening is part of a collaborative project between the CHC centers, the Child Neuropsychiatry Clinic (CNC) and the Child Habilitation units in Gothenburg (Nygren, Cederlund, et al., 2012). The overall aim is to identify young children with suspected ASD, and to implement interventions at an early stage. The screening consists of (1) language screening with (a) direct observation of the child, performed by the nurse using toy objects and (b) a parent questionnaire about early language milestones and, (2) an autism screening consisting of (c) a five-item joint attention observation (JA-OBS) and (d) the Modified Checklist for Autism in Toddlers (M-CHAT) (Baron-Cohen, Allen, & Gillberg, 1992; Robins & Dumont-Mathieu, 2006). The M-CHAT comprises a 23 items yes/no parent report with follow-up interview. If ASD is suspected after the screening, children are referred to the CNC for further assessment. Children who fail the language, but not the autism screening, are referred to a speech and language pathologist and for hearing assessment.

In this study, we present the developmental profiles of those children who were referred to and assessed at CNC because of suspected ASD following screening at the Gothenburg CHC centers between 2009 and 2011. The cohort will be followed into school age and future studies will document the further development of the children.

2. Aims

The aim of the study was to describe the clinical profiles of a group of preschool children screening positive for ASD in a community surveillance program with respect to a broad panorama of developmental disorders and problems. The children in the cohort were then compared with a non-screened Swedish preschool cohort with ASD, with a view to establishing any differences in clinical profile or age at diagnosis across community-screened or non-screened ASD cases.

3. Materials and methods

3.1. Screening and subjects

The screening procedure at the age of 2.5 years at the CHC center consisted of (1) brief language screening (Miniscalco, Nygren, Hagberg, Kadesjö, & Gillberg, 2006), (2) the M-CHAT (Baron-Cohen et al., 1992, modified version Robins & Dumont-Mathieu, 2006), and (3) a joint attention observation (JA-OBS) performed by the CHC nurse, who had received targeted "ASD training" in order to increase ASD awareness (Nygren, Sandberg, et al., 2012). A nurse and/or a pediatrician evaluated the results. All nurses at the CHC centers had been personally instructed to refer all screen positive cases for such neuropsychiatric assessment to one and the same clinic (i.e. the CNC), for further in-depth assessments.

During 2009–2011, a total of 134 children under age four years with suspected ASD following screening at CHC centers in Gothenburg were referred to the CNC for such assessments. Parents of 129/134 provided written informed consent to have their child participate in the assessment program at the CNC. Three children did not turn up for their booked assessment, and two moved abroad before assessment could take place.

The 129 children were born between 2005 and 2008 and were between 19 and 49 months of age (mean 35.3 months) at the start of the assessment at the CNC. The boy:girl ratio was 3.8:1 (102 boys and 27 girls). More than three in five (62% – 80/129) of the study group had at least one parent coming from a country outside Sweden. A total of 28 families needed an interpreter during the assessment. In nine families, the assessment was performed in English.

3.2. In-depth diagnostic assessments at the CNC

A team of professionals with several-many years of experience of working with children with ASD and other neurodevelopmental disorders performed the assessment. The team consisted of at least one physician (pediatrician or child