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Young children who screen positive for autism: Stability, change and "comorbidity" over two years

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a developmental disorder with a wide variety of clinical phenotypes and co-occurrences with other neurodevelopmental conditions. Symptoms may change over time.
Aims: The aim of the present study was to prospectively follow 96 children, initially assessed for suspected ASD at an average age of 2.9 years.
Methods and procedures: All children had been identified with autistic symptoms in a general population child health screening program, and had been referred to the Child Neuropsychiatry Clinic in Gothenburg, Sweden for further assessment by a multi-professional team at Time 1 (T1). This assessment included a broad neurodevelopmental examination, structured interviews, a cognitive test and evaluations of the childís adaptive and global functioning. Two years later, at Time 2 (T2), the children and their parents were invited for a follow-up assessment by the same team using the same methods.
Outcomes and results: Of the 96 children, 76 had met and 20 had not met full criteria for ASD at T1. Of the same 96 children, 79 met full ASD criteria at T2. The vast majority of children with ASD also had other neurodevelopmental symptoms or diagnoses. Hyperactivity was observed in 42% of children with ASD at T2, and Intellectual Developmental Disorder in 30%. Borderline Intellectual Functioning was found in 25%, and severe speech and language disorder in 20%. The children who did not meet criteria for ASD at T2 had symptoms of or met criteria for other neurodevelopmental/neuropsychiatric disorders in combination with marked autistic traits. Changes in developmental profiles between T1 and T2 were common in this group of young children with ASD. The main effect of Cognitive level at T1 explained more than twice as much of the variance in Vineland scores as did the ASD subtype; children with IDD had significantly lower scores than children in the BIF and AIF group. Co-existence with other conditions was the rule.
Conclusions and implications: Reassessments covering the whole range of these conditions are necessary for an optimized intervention—adapted to the individual child's needs.

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What this paper adds

The children in our study cohort were initially screened for symptoms of ASD in a community-based surveillance program at age 2.5 years. 93% of all with and ASD-diagnosis at T1 had an ASD-diagnosis two years later. Of those who had screened positive for ASD but who were not given an ASD diagnosis at T1, 40% met criteria for ASD two years later. 71% of ASD diagnoses were stable from T1 to T2, as were 60% of IDD diagnoses. ASD symptoms and cognitive levels were either stable or changed during the observed period, but there were always symptoms within the field of ASD or other ESSENCE two years after the first assessment. All children with Non-ASD ESSENCE at T1 still had ESSENCE-problems including autistic features at T2. Almost all the children with ASD also had Non-ASD ESSENCE problems at T2.

The findings underline the concepts of ESSENCE and autism plus. Broad neurodevelopmental/neuropsychiatric assessments and follow-up are clearly required for children with suspected ASD so as to guarantee a basis for optimal early and appropriate interventions. The risk of "over-diagnosis" of ESSENCE/ASD problems by screening for ASD at 2.5 years appears to be minimal.

1. Introduction

Autism spectrum disorder (ASD) is a developmental disorder with a wide variety of clinical phenotypes and "comorbidities". The core symptoms of ASD are early onset difficulties in the field of social communication and social interaction, combined with limited interests, activities or play (DSM-5, American Psychiatric Association, 2013). Early identification and intervention are considered important (Dawson & Gernsbacher, 2010; Eikeseth, 2009; Reichow, Barton, Boyd, & Hume, 2012; Hedvall et al., 2014). There are considerable differences regarding prevalence and severity of symptoms across cases within the autism spectrum and the same individual may over time show significant changes with regard to symptom profile and diagnostic criteria met (Daniels et al., 2011; Hedvall et al., 2014). More knowledge is needed with regard to factors underlying the heterogeneous developmental pathways and outcome seen in children with ASD (Fountain, Winter, & Bearman, 2012). Autism very often co-occurs with other neuropsychiatric and neurodevelopmental disorders such as language disorder, developmental coordination disorder (DCD), tic disorders, attention-deficit/hyperactivity disorder (AD/HD), intellectual developmental disorder (IDD) and epilepsy (EP). These overlapping conditions are now often referred to as ESSENCE (Early Symptomatic Syndrome Eliciting Neurodevelopmental Clinical Examinations; Gillberg, 2010). The importance of screening young children with ASD for comorbid psychiatric conditions has been emphasized (Horovitz, Matson, & Sipes, 2011; Fernell et al., 2014). This means that early identification of ASD also requires characterization of comorbidities, so that these may also be targeted for early intervention. Of particular importance is the childís general cognitive level (Hedvall et al., 2014). The baseline cognitive ability is crucial for the outcome trajectories of children with ASD; in prospective studies, significant gains in adaptive skills were found only for those with DQ $\geq$70 (Ben-Itzchak, Watson & Zachor, 2014; Fernell et al., 2011).

In Sweden, children are regularly followed at Child Healthcare Centers (CHC) during their first six years of life, for immunizations, health checks and developmental surveillance at certain key ages. About 95–99% of the children in the Gothenburg area, South-west Sweden, participate in such surveillance programs (Arvidsson, Holmberg, Reuter, & Strömbom, 2010). Since 2008 there is a language and communication screening, together with a screening for ASD, at the age of 2.5 years (Nygren, Sandberg et al., 2012). The screening is part of a collaborative project between the CHC centers, the Child Neuropsychiatric Clinic (CNC) and the habilitation centers in Gothenburg (Nygren, Cederlund et al., 2012). The aim of the CHC screening is to identify children with suspected ASD, to initiate further assessments at the CNC and, if ASD is confirmed, to refer the child to the habilitation center for early interventions (Kantzer, Fernell, Gillberg, & Miniscalco, 2013). In the present study, we describe the developmental profiles, and the ESSENCE-related symptoms in a group of preschool children with ASD followed for two years from their first assessment after positive autism screening at the CHC.

2. Aim

The aim of the study was to describe the developmental and clinical profiles of this two-year- follow-up group of 96 young children, who had screened positive for autism at CHC and thereafter been diagnosed with ASD (Time 1, T1). The stability and change of the ASD diagnoses and the prevalence of other ESSENCE-related symptoms and difficulties were analyzed at Time 2 (T2).

3. Materials and methods

3.1. Screening and subjects

During 2009–2011, a total of 134 children under the age of four years with suspected ASD after screening at the CHC in Gothenburg were referred to the CNC for further, detailed ASD assessment at a mean age of 2.9 years (T1). Details of the screening procedure using the M-CHAT (Robins & Dumont-Mathieu, 2006) and various other measures have been published by Nygren, Sandberg et al. (2012), and Nygren, Cederlund et al. (2012). Parents of 129 of the 134 children provided written informed consent to have their child participate in the assessment program at the CNC. One hundred of these children met criteria for ASD, 29 had marked autistic traits (AT), other ESSENCE-related symptoms or both (Kantzer et al., 2013).

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