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BRIEF REPORT: Exploring the Characteristics of Children with a Diagnosis of PDD-NOS

Abstract

The purpose of this study was to examine the diagnostic and developmental profiles of 105 children given a PDD-NOS diagnosis. Four subgroups were formed based on the reason for the PDD-NOS diagnosis (fewer than 6 criteria, fewer than 2 social criteria, no repetitive behaviours, and other). Cognitive level, adaptive functioning, autism severity, and the number of DSM-IV autism criteria were examined, but the four subgroups did not differ on any developmental or diagnostic variables. Results suggest that the PDD-NOS group is very heterogeneous.

The Pervasive Developmental Disorders (PDD) category of the Diagnostic and Statistical Manual (DSM-IV) includes four specific diagnoses: Autistic Disorder (AD), Asperger syndrome (AS), Rett Disorder, and Childhood Disintegrative Disorder; all of which are characterized by impairments in reciprocal social interactions, communication, and the presence of stereotyped behaviours, interests, and activities (American Psychiatric Association [APA], 2000). In addition, like other categories in the DSM-IV, there is a "not otherwise specified" diagnosis, PDD-NOS, for children who do not meet criteria for one of the specific PDD diagnoses. Considering the high prevalence rate of PDD-NOS (15/10,000; Fombonne, 2003), it is important that we gain a clearer understanding of this diagnosis, which is often confusing for parents and service providers alike.

Efforts have been made to better understand PDD-NOS by comparing it to AD and AS. Buitelaar, Vander Gaag, Kiln, and Volkmar (1999) reported that PDD-NOS is a more heterogeneous category than AD. Matson, Dempsey, and Fodstad (2009) found better verbal communication and social relationships in the PDD-NOS group as compared to the AD group. Perry, Condillac, Freeman, Dunn-Geier, and Belair (2005) showed that children with PDD-NOS have significantly lower autism severity (as measured by the Childhood Autism Rating Scale, or CARS) than children with AD.

Walker et al. (2004) reported that children with PDD-NOS have more delayed language than children with AS, fewer repetitive behaviours than both children with AD and AS, and fewer social difficulties than children with Asperger's. The cognitive functioning of the PDD-NOS group was between that of the AD and AS groups. Walker et al. (2004) also identified three subgroups within their sample of 20 children with PDD-NOS: 1) children with good language functioning and many repetitive behaviours; 2) children with little or no repetitive behaviour; and 3) children who had a late age of onset, were too young, or too delayed to diagnose conclusively.

The purpose of the present study was to examine the diagnostic and developmental profiles in a much larger group of children with PDD-NOS. First, we examined the characteristics of the children in the sample, specifically: age, gender, autism severity, DSM-IV AD criteria met/not met, cognitive level, and adaptive behavior level. Second, we looked at the various reasons that led to the PDD-NOS diagnosis. These reasons were then used to identify subgroups within the larger PDD-NOS sample and to document the relative frequency of these subgroups. Finally, we compared the subgroups to determine whether they differed on the developmental and diagnostic variables.

Method

Participants

The data for this study were obtained through a retrospective file review of assessments completed at York University, the Treatment, Research and Education for Autism and Developmental Disorders (TRE-ADD) Program at Thistletown Regional Centre, Surrey Place Centre, and the Children's Hospital of Eastern Ontario. The total sample size was 105 children, all with a diagnosis of PDD-NOS. The children ranged in age from 2 to 12 years (M = 63.31 months; SD = 24.68). The clinical diagnoses were made by one of four experienced psychologists based on all available information (developmental assessment, parent interview, and observation of the child). Ethics approval for this project was obtained through York University as well as all three service organizations.

Measures

The Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) or VABS-II (Sparrow, Cicchetti, & Balla, 2005) were used to assess the children's adaptive functioning in communication, daily living skills, and socialization. As is common practice in this population because of clients' heterogeneity, one of several measures was used to assess cognitive level (whichever was most clinically appropriate): the *Mullen Scales of Early Learning* (MSEL; Mullen, 1995), the *Bayley Scales of Infant Development* (Bayley, 1993), the *Stanford-Binet Intelligence Scale: Various Editions* (Roid, 2003; Thorndike, Hagen, & Sattler, 1986), the *Wechsler Preschool and Primary Scale of Intelligence (3rd ed.)* (WPPSI-3; Wechsler, 2002), or the *Leiter International Performance Scale: Revised* (Roid & Miller, 1997). *The Childhood Autism Rating Scale* (CARS; Schopler, Reichler, & Renner, 1988) was used to measure autism severity. A DSM-IV Checklist for AD criteria was also completed to determine which specific criteria were met.

Results

The developmental and diagnostic characteristics of the children in the sample varied widely (see Table 1).

Four mutually exclusive reasons for receiving a PDD-NOS diagnosis were identified: 1) meeting fewer than 6 Criteria for AD; 2) meeting fewer than 2 social criteria but 6 or more overall; 3) not meeting any of the repetitive/stereotyped criteria; 4) other or unclear. Figure 1 shows the percentage who received the diagnosis for each of these reasons.

One-way ANOVAs were used to compare developmental and diagnostic characteristics across subgroups (i.e., age, adaptive behavior, cognitive level, autism severity). There were no significant differences among the four subgroups for any of the diagnostic and developmental variables.

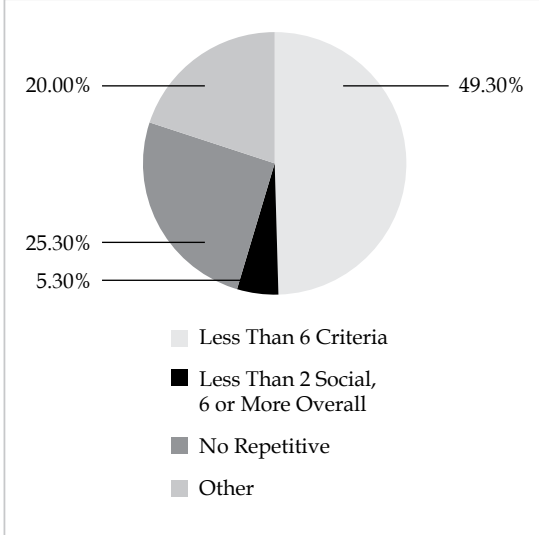

Figure 1. Characteristics of children with PDD NOS (%)

Table 1. Characteristics of Children with PDD-NOS

	M (SD)	*Range*
Total CARS score	28.31 (4.04)	20–40
Total # DSM-IV AD criteria met (/12)	4.97 (1.22)	3–8
Cognitive level (standard scores)		
Full scale IQ	62.62 (22.84)	14–111
Verbal IQ	68.80 (24.49)	11–109
Non-verbal IQ	79.41 (27.09)	17–136
VABS or Vineland-II (age equivalents)		
Communication domain	33.17 mo (22.42)	2 mo–97 mo
Daily Living Skills domain	37.51 mo (23.51)	12 mo–120 mo
Socialization domain	26.84 mo (18.20)	6 mo–103 mo

Discussion

This study builds upon the limited body of existing research on the characteristics of children with a diagnosis of PDD-NOS. Our results suggest that the PDD-NOS group, as a whole, is quite heterogeneous in its presentation, a finding in agreement with previous studies (Buitelaar et al., 1999; Walker et al., 2004). There was great variation found in the number of DSM autism criteria met, the severity of autism, cognitive level, and the level of adaptive functioning for the children in our sample.

Subgroups based on a typology of reasons for giving the PDD-NOS diagnosis did not differ systematically on developmental or diagnostic variables. It is possible that significant differences were not found between the four subgroups due to the way in which the subgroups were identified, which was on the basis of clinical judgment using DSM autism criteria. It is possible that different subgroups would be derived if statistical methods were employed to extract the groups based on scores on individual items on the various diagnostic tools, although the sample size might not allow for that type of analysis. The absence of significant differences among the subgroups may also be a result of the specific measures used to assess differences. It is possible that these measures do not explore the qualitative differences observed in clinical settings among children with a PDD-NOS diagnosis sensitively enough. Lastly, the lack of significant findings may be the result of the uneven sizes of subgroups being compared, especially since one of the groups was composed of only four children. It is important to note, however, that the main strength of this study lies in its large PDD-NOS sample size relative to others in the literature.

The proposed DSM-V criteria for autism spectrum disorder (currently posted for comment at www.dsm5.org) would result in PDD-NOS no longer being used as a diagnosis, presumably, based on the argument that specific diagnoses within the autism spectrum are not reliably differentiated. Results from this study provide no strong argument against this change.

These findings speak to the importance of recognizing that all children with a PDD-NOS diagnosis are not the same. Treatments and supports should always be individualized to the person's strengths and needs, in any case.

Key Messages from This Article

People with disabilities: Every person with a label of PDD-NOS is an individual and should be treated as such.

Professionals: PDD-NOS is a very heterogeneous diagnosis and it is important to plan treatment based on individual strengths and needs rather than the diagnosis.

Policy makers: Decisions regarding eligibility for services should be carefully considered given the lack of diagnostic precision and the wide variability in the needs of the population served.

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