

# Diagnosis of pervasive developmental disorders: when and how? An area-based study about health care providers

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Veneto Region, Italy

**Background:** Pervasive developmental disorders (PDDs) can be very difficult to diagnose in children and to communicate such a diagnosis to their parents. Families of children with PDD learn of their child's diagnosis long after the first symptoms are noted in the child's behavior.

**Methods:** An area-based survey was conducted to assess all social and health care providers taking care of patients with PDDs in the Veneto Region (North-East Italy).

**Results:** Only 28% of health care providers arrived at a definite diagnosis when the child was in his/her first year of age, 51% when the child was 2-3 years old and 21% from age of 4 years and up. On average, the latency between the time of the diagnosis and its communication to the family was 6.9 months. However, a number of families did not ever have a diagnosis communicated to them. Sometimes, 68% of the providers did not communicate a PDDs diagnosis to patient's families, and 4% of them quite commonly.

**Conclusion:** The well-known delay in making a diagnosis of PDDs has two distinct components: one relating to the difficulty of confirming a diagnosis of PDDs, the other, hitherto unrecognized, relating to the family being notified.

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**Key words:** autism, pervasive development disorders; classification system; communication; diagnosis

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## Introduction

Since Kanner's first report, children with pervasive developmental disorders (PDDs) have been labeled as having various syndromes and diseases, such as "childhood psychosis", "schizophrenia", "symbiotic psychosis", etc. Nowadays the different conditions coming under the umbrella term of PDDs are classified using standardized systems, which serve as gold standards for their diagnosis. The International Classification of Diseases (ICD) released by the World Health Organization<sup>[1]</sup> and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) produced by the American Psychiatry Association<sup>[2]</sup> are fundamental references.<sup>[3]</sup> The Fifth Edition of DSM (DSM-5) has been recently released at the American Psychiatric Association's Annual Meeting in May 2013. Classification of PDDs has been revised, considering the concept of "broader phenotype" of autism. PDDs have been replaced by a single umbrella group: "autism spectrum disorder" (ASD). The new classification aims to increase the specificity. Some clinicians and researchers have concern about it. DSM-5 ASD does not specifically state what a minimum number of criteria under social/communication domain must be endorsed to have a ASD. Moreover, using an umbrella term ASD risks to hide patients' clinical heterogeneity and to threaten services delivery.

Other more specific pediatric classification systems have been released, such as the French CFTMEA, classification française des troubles mentaux de l'enfant et de l'adolescent,<sup>[4]</sup> and the Diagnostic Classification of Mental Health and Development Disorders of Infancy and Early Childhood called "Zero to Three".<sup>[5]</sup> Physicians are scarcely familiar with such classification systems.<sup>[6]</sup> Wiggins, Baio, and Rice<sup>[7]</sup> found that 70% of practitioners use no diagnostic tools when assessing patients suspected of having a PDD.

The symptoms of PDDs appear in early infancy in approximately two thirds of cases, and parents are the first to suspect that something is wrong, often before the child is 20 months of age.<sup>[8,9]</sup> The mean age at diagnosis has decreased, but many children are still not diagnosed until they are four years old,<sup>[10]</sup> or even later, up to 10

years old,<sup>[7,11]</sup> although early intensive treatment would be more effective.<sup>[6,12]</sup> Parents perceive this diagnostic in delay, and Harrington et al<sup>[13]</sup> assessed it at a median of 9 months.

The reasons for such a diagnostic delay are not fully understood and the timing of its communication to parents might be involved in the causal chain. Most research dealing with the timing and problems of communicating a diagnosis is concerned about patients in the oncological or palliative settings, while the literature is scanty about PDDs.<sup>[14]</sup>

The present study focused on the diagnostic process for patients with PDDs and the communication of a diagnosis to their families in the Veneto Region (North-East of Italy, about 4.8 million inhabitants), with the following in particular: (1) the tools used by professionals to diagnose PDDs; (2) the timing of the diagnosis and its communication to the family; and (3) determinants of communication latency.

## Methods

### Health care pathway for PDDs in Italy

The Veneto Region has nearly 5 millions inhabitants, 18% of them are at age of 0-18 years. The public health system in the Veneto Region comprises 21 health care units (88 hospitals and 56 primary care centers) and 2 hospital administrations that provide care for patients with both acute and chronic diseases under a social and health integrated service. All residents have access to the health providers of the national health system, which are public and almost entirely free of charge.

A diagnosis of PDDs can be confirmed by physicians working both in hospitals (pediatric and child and adolescent psychiatry wards) and in primary care settings. Each child's health care is managed by a family pediatrician, and children with chronic diseases are managed also through primary care centers that specialize in more specific health providers (e.g. child and adolescent psychiatry health services). Each step of the diagnostic and treatment pathway is almost entirely free of charge, even when the diagnosis is undetermined and shared with parents through the individual health care plan of the patient and his/her family. The proper and prompt communication of a diagnosis is a duty of all physicians as defined in their ethical code, and the diagnosis must be communicated at the cognitive level and developmental stage of the patient in mind.

### The survey

An area-based survey was conducted to assess social and health care providers involved in providing care to children with PDDs, and to analyze the number of cases

they deal with, how they are organized, and their health care pathways. Permission to conduct the survey was obtained from the regional administration in charge of health care providers' management and organization.

An ad hoc semi-structured questionnaire was used to deal with the following issues: a) The number of patients followed per typology of diagnosis; the proposed diagnoses were included in the available classification systems (ICD, DSM, CFTMEA, Zero To Three) together with other unclassified diagnoses such as "autistic traits" to study the accuracy and pertinence in diagnosis by health providers; b) The classification systems allowed for more than one possible answer; c) Non-communication of a diagnosis to the family and how probable it is with five possible answers ("never", "possibly", "rarely", "frequently").

The questionnaire was administered to managers of all social and health care providers of the region taking care of PDDs patients, through the chief executive officers of the 21 health care units of the region.

### Data processing and statistical analysis

Data from both questionnaires were managed in Microsoft Access software (Microsoft Corp., Redmond, WA, USA). Statistical analyses were performed with the SAS package, rel. 9.2 (SAS Institute Inc., Cary, NC, USA) and addressed the following points: a) The diagnostic tools used by health care providers were compared with the types of diagnosis they established, assessing the consistency between the classification tools used and the diagnoses; b) The latency between the time of the diagnosis and its explicit communication to the family. This analysis was conducted with consideration of the child's age when the health care providers established a definitive diagnosis (in three age groups: 0-1, 2-3, and <18 years old). The answers to questions about whether the health care providers were always able to communicate the diagnosis to parents, and whether the provider might decide not to do so were analyzed; c) The latency in communicating the diagnosis was determined. Two multivariable analyses were subsequently performed while using two logistic regression analyses to identify influential factors: one concerning the latency in the communication of the diagnosis to parents once it had been established (time  $\geq 6$  months), and the other relating to the possibility of the parents never being told the diagnosis. Both logistic regression analyses were made using the stepwise method (the entry significance level at 0.25 and the stay significance level at 0.20). The covariates used were: the adoption of international classifications (ICD 10, DSM-IV, CFTMEA, Zero to Three), the type of health providers (Child and Adolescent Psychiatry Health Services, Adult Psychiatry Health Services, Districts

Health and Social Health services, Autism Centers, hospital wards), the type of diagnosis (generalized developmental disorder, autism, atypical autism, pervasive developmental disorder, autistic traits, other clinical diagnoses in the same group, dysthymic psychosis, undefined diagnosis), and the child's age at diagnosis (0-1; 2-3; <18 years).

Categorical data are shown as numbers with percentages, and continuous data as means, medians and ranges.

For the parameters in each of the two logistic regression analyses, we calculated the standard error (SE), odds ratios (ORs) and 95% confidence intervals (CIs), significance, and goodness of fit. A *P* value less than 0.05 was considered statistically significant.

## Results

### Diagnostic tools

In 52 health care providers in the Veneto Region's health system providing care for 1749 patients with PDDs, there are different typologies: neuropsychiatric services (19), psychiatric departments (7), disability or handicap services (5), rehabilitation services (3), services of local social-health unit (15), and autism centres (3). Different professionals are working within them: psychologists (94% of services), child neuropsychiatrists (81%), speech therapists (65%), and social assistants (65%). Instead, neurologists (6%), pediatricians (10%) and psychiatrists (13%) are less often present.

The diagnostic labels most often used are generalized developmental disorder (34%), autism (23%), psychotic disharmony (13%), and autistic traits (10%).

At least, one diagnostic classification system is used in 85% of the health care providers, the most

often used being ICD-10 (75%). The types of diagnosis reported were compared with the classification systems reportedly adopted to assess the consistency between them (Table 1): the health care providers using the diagnostic categories in the ICD-10 or DSM-IV claimed that they used them with a consistency ranging from 80% to 100%, while the health care providers adopting the CFTMEA from 0 to 15%. Moreover, 26 health care providers (50%) used the diagnostic label "autistic traits", 12 (23%) used the term "undefined diagnosis", and 9 (17%) used an aspecific diagnosis (e.g. "cerebroopathy").

### The latency between the time of the diagnosis and its explicit communication to the family

Most health care providers arrived at a definitive diagnosis of PDDs in the child's preschool years: 28% "0-1 years old", 51% "2-3 years old" and 21% "18 years old" (15% "4-5", 4% "6-13" and 2% "14-17").

Time elapsed between the definitive diagnosis being established and its notification to parents (mean 6.9, median 6 months), but this interval varied owing to child's age at diagnosis (Fig. 1). If the diagnosis was

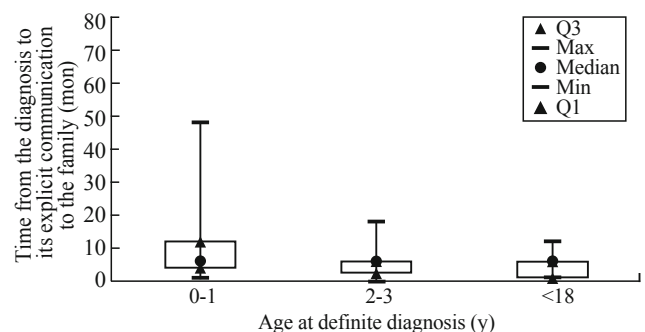


Fig. 1. Latency of communication of the diagnosis to the family.

**Table 1.** Types of diagnoses used by the 52 health care providers in the Veneto Region and their consistency with standard classification systems

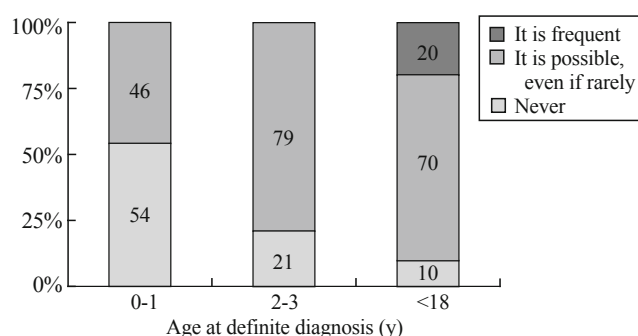
Types of diagnosis (classifications including the diagnosis)	Health care providers using the diagnosis	Health care providers using the diagnosis and its correct classifications, <i>n</i> (%)
Generalized dev. disorder (ICD-X, DSM-IV)	37	32 (86)
Autism (ICD-X, DSM-IV, ICD 9 CM, DSM-III-R, CFTMEA)	30	27 (90)
Psychotic disharmony (CFTMEA)	24	3 (12)
Precocious deficit psychosis (CFTMEA)	20	3 (15)
Adolescent-onset schizophrenic psychosis (CFTMEA)	9	0 (0)
Atypical autism (ICD-X)	10	8 (80)
Rett syndrome (ICD-X, DSM-IV)	9	9 (100)
Childhood-onset schizophrenic psychosis (CFTMEA)	13	0 (0)
Asperger syndrome (ICD-X, DSM-IV)	12	12 (100)
Disintegrative dev. disorder (ICD-X, DSM-IV)	10	9 (90)
Kanner syndrome (ICD-X, ICD-9 CM)	3	3 (100)
Dysthymic psychosis (CFTMEA)	2	0 (0)
Autistic traits* (None)	26	-
Undefined diagnosis* (None)	12	-
Other* (None)	9	-

\*: diagnosis present in no classification tool. dev.: development.

established within the first 2 years of life, the health care providers took longer period to notify parents (from 1 month to 4 years; mean 9.8, median 6 months). If the diagnosis was reached when the child was 2-3 years old, this latency in communicating the diagnosis was shorter (from no delay to 1.5 years; mean 5.8, median 6 months). The latency dropped further for children aged 4-18 years at the time of their diagnosis (in this case parents are told within 12 months; mean 5.5, median 6 months).

Health care providers did not always communicate the diagnosis to parents, i.e., 68% of the health care providers reported that sometimes, albeit rarely, the diagnosis would never be communicated to the family, and 4% of the health providers said this was quite common. As shown in Fig. 2, the older the patient's age at the time of establishing a definitive diagnosis by the health care providers, the less likely the health care providers were to notify the diagnosis to the family. For children up to 2 years of age, 54% of the health care providers said this was never the case, and 46% said it happened only rarely, whereas for children of 2-3 years old at the time of their diagnosis, these percentages rose to 21% and 79%, respectively. For persons aged up to 18 years, only 10% of the health care providers always notified parents of the diagnosis, 70% did so rarely, and 20% did not do so at all.

**Determinants of latency in communicating the diagnosis**  
Table 2 shows the results of our logistic regression



**Fig. 2.** The diagnosis maybe never be communicated to the family.

analysis assessing the determinants of the latency period in communicating a diagnosis of PDDs to parents. Health care providers taking care of patients with a diagnosis of autism (OR=24.62;  $P=0.008$ ) or other diagnoses in the same diagnostic group (OR=62.90;  $P=0.057$ ) took longer time to communicate the diagnosis, whereas those using such diagnostic categories as generalized developmental disorder (OR=0.07;  $P=0.048$ ), atypical autism (OR=0.05;  $P=0.053$ ), disintegrative developmental disorder (OR=0.12;  $P=0.10$ ), or psychotic disharmony (OR=0.22;  $P=0.15$ ) did so more quickly. The child's age when the diagnosis was established was fitted into the model as a predictive factor. The health care providers diagnosing cases of PDDs in children up to 2 years old took longer time to notify the family (OR=14.55;  $P=0.053$ ).

As for the classification tools used, the health care providers using Zero to Three were likely to communicate the diagnosis sooner than those using the DSM IV (OR=0.12;  $P=0.11$ ). Table 3 shows the logistic regression analysis used to assess the determinants of the likelihood (as reported by the health providers) of the health care providers never communicating the diagnosis to the child's parents. Health care providers diagnosing "autistic traits" (OR=38.72;  $P=0.020$ ) or

**Table 2.** Stepwise logistic regression analysis on the latency of the communication of the diagnosis to the family\*

Characteristics	Parameter	OR	95% CI	P value
Intercept	1.61	-	-	0.200
Use of DSM IV	1.24	3.40	0.43-27.66	0.242
Use of Zero to Three	-2.06	0.12	0.01-1.56	0.106
Generalized developmental disorder	-2.59	0.07	0.006-0.98	0.048
Autism	3.20	24.62	2.30-262.86	0.008
Atypical autism	-2.92	0.05	0.003-1.04	0.053
Disintegrative developmental disorder	-2.11	0.12	0.009-1.61	0.110
Psychotic disharmony	-1.51	0.22	0.03-1.76	0.153
Other clinical diagnosis in the same group	4.14	62.89	0.88-999.99	0.057
0-1 y of age at diagnosis	2.67	14.55	0.96-219.48	0.053

\*: Time from the diagnosis to its communication greater than or equal to 6 months. CI: confidence interval; OR: odds ratio.

**Table 3.** Stepwise logistic regression analysis on the likelihood of the diagnosis never being communicated to the family

Characteristics	Parameters	OR	95% CI	P value
Intercept	0.65	-	-	0.531
Child and Adolescent Psychiatric Services	-3.42	0.03	0.002-0.48	0.012
Psychotic disharmony	-3.48	0.03	0.001-0.83	0.038
Autistic traits	3.65	38.71	1.80-833.05	0.019
Undefined diagnosis	1.67	5.32	0.38-73.05	0.210
0-1 y of age at diagnosis	-3.34	0.03	0.002-0.62	0.022
Latency >3 mon in communicating the diagnosis	2.91	18.48	1.21-282.20	0.036

OR: odds ratio; CI: confidence interval. Likelihood ratio test:  $P=0.0006$ , Percent concordant: 87.5%.

"undefined diagnosis" (OR=5.33;  $P=0.21$ ) were less inclined to notify the diagnosis to the family than the health care providers diagnosing cases of "psychotic disharmony" (OR=0.031;  $P=0.039$ ). The Child and Adolescent Psychiatry Services emerged as a factor protecting against the risk of parents not being notified with an odds ratio of 0.032 ( $P=0.013$ ), and the same was true for the younger patients (0-1 years) at the time of the diagnosis (OR=0.035;  $P=0.023$ ). Finally, health care providers tending to report a longer latency in communicating the diagnosis to the family also emerged as being more likely not to notify parents at all (OR=18.48;  $P=0.036$ ).

## Discussion

This study showed a marked variability in the diagnosis of PDDs in a representative sample of Italian health care providers. The 52 health care providers in the Veneto Region dealing with such patients tended to use to different classification systems in the diagnosis of cases of PDDs: 85% of them reportedly used at least one classification (usually more than one). The ICD-10 and DSM-IV were commonly used (by 75% and 55% of the health providers, respectively), but there was a marked contradiction among the types of diagnosis. They adopted diagnostic categories not included in the mentioned classification systems, and half of them used the label "autistic traits", which is not contained in any international classification system. As in other reports,<sup>[6,7]</sup> our analysis revealed scanty knowledge about the specific diagnostic tools, which is a major issue in the patient's diagnostic pathway.

The lack of a shared language, even within the same health care providers, negatively affected the quality of communication between different professionals, and between professionals and patients' families who will likely seek information and gain knowledge by themselves.<sup>[15]</sup> It takes time to establish a diagnosis of PDDs. Only 28% of the health care providers generally did so before the child was 2 years old, and 51% in the first 4 years of life of the child, and 21% until the child was 18 years old over.

Physicians agreed that PDDs must be diagnosed before 2 years of age, but many children were not diagnosed until they were 4 years old,<sup>[11]</sup> possibly because of the lack of knowledge about ASD symptomatology,<sup>[16]</sup> and/or the varied presentations of clinical cases.<sup>[17]</sup> For instance, diagnosing Asperger syndrome and PDD-NOS (not otherwise specified) takes more time than diagnosing autistic disorders,<sup>[10]</sup> and the patients are usually 4-5 years old on average in the former versus 2 years old in the latter.<sup>[18-20]</sup> Taking 18 years to reach a diagnosis of PDDs is hard to justify.

The present study was a first attempt to investigate an unknown behavior, i.e., the delay in communicating the diagnosis to parents. This can last on average 6.9 months, with a maximum of 4 years, but as many as 72% of the regional health care providers said that the parents might likely never be told the diagnosis, albeit in exceptional cases. A diagnosis of PDDs is difficult or even impossible to communicate, and the age of the child influences this issue. If the patient is a toddler, the health care providers tend to be slow to notify the diagnosis to the parents, but they always do so eventually. If the patient is an older child or adolescent, the diagnosis might be communicated straight away, or never. The diagnostic delay is a well-known problem in autism and PDDs, as well as in other geographical settings,<sup>[7,21]</sup> and several factors have been considered as determinants. The delay in diagnosing PDDs can be seen as the sum of two distinct delays, one being the well-known difficulty in reaching this diagnosis, the other (hitherto unrecognized) relating to its communication to the parents, which could be potentially infinite. The younger the child, the more health care providers are likely to arrive at a definite diagnosis and to notify the parents, but the patient's age is not the only issue involved: the diagnostic category adopted by the specialists and the type of health care providers involved also have an influence. A diagnosis of autism carries an inherent communication problem between professionals and families, likely relating to the difficulty in dealing with such disabling condition with a complex prognosis. Specialists find it is hard to communicate such a diagnosis.<sup>[22]</sup> There are lots of reports on how patients can be informed that they have a chronic and severe disease,<sup>[23-25]</sup> but it rarely refers specifically to PDDs. Professionals may not be adequately qualified to handle their own emotions in such conditions,<sup>[23,24,26]</sup> especially psychiatric disorders. In fact, parents' satisfaction with how they were told what was wrong with their children is lower when the child has a mental disorder rather than a physical disease,<sup>[27]</sup> especially when it comes to autism and PDDs.

The adoption of diagnostic labels not contemplated in any acknowledged classifications (e.g. autistic traits) and the problem of explaining such a diagnosis reflects the shortcomings in best practice and inadequacies in professional training and clinical experience of PDDs. Professionals working at dedicated pediatric health care providers (Child and Adolescent Psychiatric Health Services), with a deeper and longer standing experience of dealing with such cases, were found more likely to cope properly with the communication of the diagnosis than health care providers designed for adults, and the former were more likely to use a classification system implemented specifically for pediatric patients, such as

CFTMEA.<sup>[4]</sup>

The present study has the advantage of stemming from an area-based surveillance, providing data representative of the whole population in the Veneto Region. We assessed variables never studied previously, which were related to the timing of the communication of a diagnosis of PDDs to parents. The limitation of this study was that the data were provided by the managers of the health care providers, not by all professionals at the centers. Delayed diagnosis of PDDs was due partly to the intrinsic difficulty in diagnosing PDDs, and other factors such as professionals' hesitation to communicate such a diagnosis.

Based on educational programs dedicated to health professionals, health programming strategies need to be designed and implemented to deal with the classification systems, the available screening tools and how to use them. The communication process and patient management are especially important when patient care is transferred from the pediatric to adult health care providers.

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**Ethical approval:** Permission to conduct the survey was obtained by the Regional Administration in charge of health care providers' management and organization.

**Competing interest:** There are no competing interests to declare.

**Contributors:** FP proposed the study. MS, VDPL and FP designed the study and interpreted the data. VDPL analysed the data. MS and VDPL wrote the main body of the article with the supervision of FP. MM and GO acquired data and revised critically the paper. All authors contributed to the intellectual content and approved the final version.

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