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The Difficult Job of Parenting: Let's Talk about Parents of Children with Neurodevelopmental Disorders

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According to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), neurodevelopmental disorders (NDDs) are a large and heterogeneous group of early onset, often lifelong conditions leading to personal, social, and/or academic functioning impairments.[1] The severity of NDDs varies widely, ranging from relatively limited conditions such as specific learning disorder (involving reading, writing, and/or mathematics skills) to more complex and pervasive conditions with overall impairments of social communication skills (i.e., autism spectrum disorder—ASD) or intelligence (i.e., intellectual disability—ID).[1] According to the systematic review by Francés et al,[2] prevalences of NDDs in childhood are as follows: ID, 0.63%; ASD, 0.70%-3% (2.76% according to the most recent data from the Autism and Developmental Disabilities Monitoring (ADDM) Network in the United States of America—USA);[3] attention-deficit/hyperactivity disorder (ADHD), 5%-11%; communication disorders, 1%-3.42%; specific learning disorders, 3%-10%; and motor disorders (including, according to the DSM-5, developmental coordination disorder, stereotypic movement disorder, and tic disorders),[1] 0.76%-17%. These data, however, do not provide an idea of the overall prevalence of NDDs, given that comorbidity is very frequent among them, i.e., 2 or even more NDDs can coexist in the same individual.[1] For example, in a significant percentage of subjects with ASD, there is an associated ID (= 37.9% according to the most recent data from the ADDM Network in the USA)[3] and/or ADHD (= 32.8% according to the Neurodevelopmental Disorders Epidemiological Research Project (EPINED) performed in Spain).[4] Based on the few studies that have addressed this question, the global prevalence of NDDs in childhood ranges enormously from 4.70% to 88.50%;[2] clearly, such a wide range does not allow us to get a reasonable idea of the real global prevalence of NDDs. The large discrepancy between the reported percentages seems to be related mainly to methodological factors. In fact, only very few studies have directly assessed the children, identifying a greater number of cases than the majority of studies that merely deduce results from databases.[2] Also different countries' diagnostic habits may play a role in these large discrepancies in global prevalence data because NDDs are likely underdiagnosed in countries with greater economic difficulties.[2] To give an idea of the overall prevalence of NDDs in the USA, we can cite data provided by the National Center for Health Statistics in 2015, according to which NDDs were present in 15% of children.[2]

All this is to say that, although the overall prevalence of NDDs has not been known with certainty so far and still needs to be studied, the general probability that a parent will give birth to a child who will present with one or more NDDs appears, however, to be high, presumably above 10%. And of these children, a far from negligible proportion may present a condition of severe, chronic disability that heavily affects the quality of life of both the child and his/her family. To provide some examples, about 25%-30% of individuals with ASD do not develop a functional verbal language (so-called "minimally verbal" ones) and their social communication skills are therefore severely impaired, often leading to dysfunctional behaviors (restlessness, anger, and self- or other-directed aggression).[5] Approximately 15% of individuals with ID, i.e., those with a moderate, severe, or profound level of severity (see DSM-5 classification), have a marked cognitive impairment that determines substantial limitations

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in daily life.[1] Individuals with moderate or severe ADHD, which would be 58.1% of the total subjects with ADHD,[6] show a clinical picture leading to significant social or occupational impairment, according to DSM-5.[1] In all these NDD cases presenting a more marked disability, evidently, also the long-term prognosis regarding personal autonomy skills is poorer.

Further, in children with NDD, there is often comorbidity also with other neuropsychiatric disorders (e.g., epilepsy, insomnia, oppositional defiant disorder, anxiety, and depression) and/or internal pathologies (e.g., celiac disease and allergy disorders) that are outside of NDDs as defined by the DSM-5.[1,7] This frequent comorbidity can complicate their clinical picture even more, requiring specific diagnostic tests, making treatment more difficult, and worsening the long-term prognosis.

It should be kept in mind also that having a child with NDD can exert a negative psychological impact on their parents, particularly when the offspring's adaptive behavior is lower. Parental stress, partly related to the modification of family routines to meet the needs of children and partly related to the excruciating process of navigating the health system, is a risk factor for separation between parents.[8] In turn, separation between parents can constitute a traumatic event for the child with NDD,[8] often leading to the establishment of a vicious circle between the behavioral problems of offspring with NDD and the stress perceived by the parents. A special effort should be made to avoid the risk of social isolation in the families of children with NDD. In this sense, parental associations sometimes provide answers that the already overloaded public health system cannot provide.

Finally, we mention the possibility that a couple of parents may have 2 or even more children affected by NDD. This is not exceptional eventuality, and it could be due, on the one hand, to genetic factors which, although not yet well identified in most cases, certainly play a very important role in the etiopathogenesis of NDDs, and on the other hand, to possible environmental factors shared between the affected siblings (e.g., early exposure to air pollutants or endocrine-disrupting chemicals).[7] Having more than one affected child can obviously further increase the degree of perceived stress for parents.

The job of parenting one child (or more than one) with NDD is very often really difficult. In general, the job of parenting is risky, so to speak, if we take into account that NDDs, however frequent, are certainly not the only disorders (neuropsychiatric or otherwise) that can severely affect a child. Approaching parenthood with greater awareness of all this, thanks to better knowledge of these conditions promoted through adequate education from school age, could help future parents to mature and grow internally before any possible unexpected situations, such as raising a child with a disability, take over their lives. At the same time, research and the public health system should renew efforts to identify and, as far as possible, eliminate or limit environmental factors that may underlie NDDs and for which, theoretically, it could be easier than for genetic factors to take preventive actions. This is not to underestimate the importance of genetic tests in the study of the etiopathogenesis of NDDs, which however still lead to defining the etiology only in a minority of cases. The considerations expressed in this paper highlight the great commitment required to best manage NDDs, both in terms of care and research.

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