Global developmental delay – a delay in development of terminology

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doi: 10.1111/j.1469-8749.2011.03986.x

Once terms are published and repeatedly cited in the literature, they come to be regarded as the 'accepted' term. These terms can then be used for decades, especially in resource-poor countries where keeping up to date is less easy. Using a preliminary database search going back to 1976, the term 'global developmental delay' (GDD) is only mentioned in single case reports of syndromes. Its wider usage has only occurred since the practice parameter for GDD was published in 2003.[1] The term developmental delay is sometimes used interchangeably with GDD, and a similar preliminary online search revealed a few citations in the early 1940s.[2]

What is the entry point for GDD? What is the exit point? Why are the domains of development artificially segregated into four or five domains, where in reality each domain affects the other in bi-directional or multi-directional ways?

In the various developmental tests designed for children, the authors created various domains and scoring criteria. This is very confusing, especially for resource-poor countries where we look to the resource-rich countries for leadership. Clinicians who only have access to textbooks and not up-to-date journals have to use the tests without local standardization or validation. So-called normal development has a wide confidence interval, is subject to recall bias, and is highly affected by culture and practice in different countries. For example, Chinese children are very overprotected and not allowed to crawl freely on the floor. Similarly, children in Asian countries like China, Japan, Korea, Vietnam, and Thailand are trained to use chopsticks rather than spoons, knives or forks, but the developmental norms for chopstick use have been little studied.[3]

How should we better define our infants with delayed development – global versus partial? Should we settle with one domain and be specific, or with several domains and use additive terms?[4,5] Should GDD be a categorical or a dimensional term?

When new terminologies are introduced based upon updated evidence by expert panels, we have to be aware that most neurodevelopmental disorders are as heterogeneous as the professionals involved in the diagnostic and monitoring pathway. With technological advances in neuroimaging and genetics, for example, we should aim at regular targets for updating terminologies or classifications. We could propose that certain terminologies will need to be updated every 3 years as more scientific evidence becomes available. A standardized approach is particularly important for resource-poor countries where comparison of epidemiological data affects public health plans. Should we use the term to be 'GDD with certain features' (for example, autistic, hyperactive, hypotonic, etc.) until we can define the final etiological diagnosis? Should a child with a known condition like Down syndrome be additionally diagnosed as having GDD? Should we be defining core (major) and non-core (minor) problems in GDD?

The development of a child is an evolving, dynamic, and complex set of processes orchestrated by the brain. Multiple genetic and environmental factors can affect the growth and development of a child, in a complicated yet intertwined process that can either slow down or halt development, or perhaps regain the momentum with early intervention strategies – although there is a lack of consensus over the best early interventional strategy.

GDD is a heterogeneous term, like autism spectrum disorder or epilepsy. With advancement in diagnostic tools, these diagnostic terms are becoming more blurred and confusing. It is also difficult to revise these conceptual terms as they have been so widely adopted. For many countries we have to recognize that this diagnostic label can be equivalent to getting 'a free ticket for public service'.

An international forum was set up in Canada in 2008 to review the term GDD. The term Early Developmental Impairment (EDI; http://edii.ca/)[6] has been proposed as being compatible with the International Classification of Functioning, Disability and Health (ICF) model.[7] It is now time for all stakeholders to discuss this proposal so that it can be officially accepted or rejected. To avoid confusion, similar consensual approaches are needed for other heterogeneous disorders like autism spectrum disorders, epilepsy, or behavioral/psychiatric conditions with blurred boundaries.

After all, we do not wish to create stigmatization but rather a concise interim medical term for families to work with, before a definitive medical diagnosis can be made with relevant targeted investigations for a growing and developing child.

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