



Educating About Intellectual and Developmental Disabilities Etiology Can Serve as A Protective Factor for Patient Development



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Abstract

Throughout the following text is intended to note the importance that the different teams of clinicians and scientists working on intellectual and developmental disabilities, clearly and realistically educate families as well as those with the condition themselves, necessarily deepening in the etiology and natural history of the associated pathologies.

Understanding the specific characteristics of intellectual and developmental disabilities can work toward destigmatizing and promote greater social inclusion, by comprehending the divergences.

Keywords: Stigmatization; Etiology; Disabilities; Divergence, Intellectual disabilities

Introduction

Intellectual and developmental disabilities (IDD) are included in the most frequent conditions in the population, of which the cause is more heterogeneous. Achieving a deep knowledge of the etiology of this condition has been and remains clinically and scientifically challenging, but in the last years the advances in genetics have helped to clarify many of the IDD causes and also to understand some of the relations with other types of pathologies presented by persons with this condition [1].

However, many of these advances has not had much diffusion either at social or clinical level; consequently, the “stigma” remains as the main problem for persons with IDD and their families. While there have been several attempts during the last years to remove the stigma associated to IDD – the most representative of them is the evolution of the terminology to call this condition—several articles suggest that the stigma is still one of the main problems of the persons with IDD. The stigma promotes a negative self-perception and causes a significant worsening of caregivers and families health (specially stress and depression) and, by extension, in the conditions of living of the persons with IDD themselves [2-5].

Going deeper into the IDD etiology from a clinic perspective and educating families, close environment and society about

the natural evolution of the pathology, can contribute to a better understanding of every IDD angle, creating thereby the specific conditions of possibility to decrease the stigma and achieve the correct social integration [6]. Educating the environment of persons with IDD about the particularities of their condition can foster comprehension and empathy towards their person and their vital reality. This in turn will generate quality interactions from comprehension and respect that will encourage a quality bond between persons with IDD, their environment and their community [7].

The role of the scientific and health community is critical on this, since some articles point out that the socio-cultural context is a distinctive feature between the different ways to understand and approach the IDD and towards its future prediction [8]. Therefore, a good training and professional updating of the etiology of the diverse IDD profiles that they treat is essential; it will depend on this that the most disadvantaged or minority groups of the population have access to knowledge related to all aspects of their own condition or their relative’s condition. Scientific-clinic outreach efforts about the various advances made in every field that works on the IDD are also of great importance. This means a huge responsibility when transmitting information in an accurate and updated way to patients and their families, since for many

people the only way to access proven and supported by evidence information about their condition, is maybe through the care team [8]. It is also extremely important the role taken by associations of family members and patients, since on many occasions they are the link between the care team, the research and the society. Encouraging ties between clinicians, researchers and associations can be a good way of comprehensively approach the reality of persons with IDD and any other condition.

In conclusion, addressing the IDD from a multidisciplinary perspective and encourage the persons with this condition and their close environment to understand, know and master the etiology and the natural evolution of the associated pathologies to their own specific condition, can help to cope situations where ignorance and lack of social knowledge of the divergence, fuel the stigma and discrimination.

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