

## Ethics in Autism Care

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Autism and autism spectrum disorders (ASDs) are now recognized as an urgent public health problem [1], as their prevalence continues to increase until now current rates of 11.3 per 1,000 children in US [2]. The social impact of ASDs is highly problematic, as these pathologies negatively affect parent and family life [3]. It has been reported increased stress and mental and physical health problems in parents of autistic children compared with parents of typically developing children [4]. Furthermore, one autistic patient is very expensive for health system, as the estimated total lifetime societal cost of caring is \$3.2 million US dollars [1].

Due to the particular “social” status of an autistic patient, ethics in approaching autism and its treatments and research gain much consideration. There are many problems to be faced by relatives of autistic people, with consequences on the quality of life of all members of the family. Recent evidences indicate a negative impact on the employment of the parents of children with autism, with an increasing percentage of mothers that had to leave work or reduce it. The burden of care and surveillance amounts to an average for the family to 17.1 hours/day [5]. Autism is a disorder that persists throughout the entire existence, so that, autistic people need, throughout their life, continuous protection, assistance, as well as, prolonged specialized services and opportunities for independent adult life by the family. Psychological intervention in the clinical management of ASDs is a priority. Once a child is diagnosed of autism, many hours per week are requested to perform an optimal treatment and structured behavioural and educational intervention, often at overwhelming expense to families. Applied Behaviour Analysis (ABA), a program that uses a one-on-one teaching approach that reinforces the practice of various skills, is now recognized as the most effective psychological treatment. ABA programs are usually performed in a child's home under the supervision of a behavioural psychologist. However, ABA programs can be very expensive and have not been widely adopted by school or healthcare systems. The family also takes care of this aspect.

Unfortunately, too many autistic children and adolescents are still excluded from education system, and cannot achieve any form of assistance outside of parental care. This fact could strongly influence the onset of their adolescence and adulthood. The loss of an appropriate perspective of a dignified adulthood, together with a prospective of marginalization, increases the stress and the sense of guilt and helplessness of the family.

Autism is a relatively new disease. Since the first diagnosis described by Kanner [6], the scientific understanding of its pathophysiology has been revisited, transformed and disputed strongly influencing ethics and parental consciousness. In the middle of the twentieth century, the “refrigerator mother” hypothesis, a psychogenic explanation for autism aetiology, charged the mothers for more than a generation, with a deeply impact on mothers' consciousness [7]. More recently, the vaccination or vaccine preservatives hypothesis as primary etiologic factor in ASDs highlighted the controversial issue between the communication of scientific findings and etiologic risk. It follows that the ethical and risk communication issues associated with scientific findings on autism need to be carefully checked and implemented, as they have enormous implications for public health, for biomedical ethics, and, of course,

for the children, adults, and families affected by the disorders. Too often, in the common feeling, autism is still recognized as an unknown obscure syndrome. In a recent survey in Italy, it has been seen that three out of four Italians still think that autistic persons should have some artistic genius or mathematics, and about 63% of Italians have an image of disability solely in terms of limitation of motion, implicitly underestimating the difficulties of those who, like the person with autism, has no motor difficulty. Moreover, about autism, confusion and stereotypes still prevail, increasing the isolation of people with autism and their families [8].

International guidelines, as recommendations for clinical practice derived from scientific data, for care of autistic individuals and their families are needed, but it is noteworthy to consider that such guidelines must be grounded in a dialogue among and between concerned professionals and those primarily affected [9]. Even if scientific research on autism is taking many efforts to develop new and effective tools for early detection, diagnosis and care, patients with ASDs are still under-represented or absent from research programs in many countries. Much consideration should be addressed by healthcare systems on social ethics in autism and on family requests.

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