



Long-term outcome of autism spectrum disorder

Otizm spektrum bozukluğunun uzun vadeli sonuçları

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Abstract

In most cases, autism spectrum disorder is a life-long condition, often severely affecting the quality of life of the patient and his/her family, but nowadays this diagnosis should not be considered a final sentence without appeal. Although even today the recovery from the autism spectrum is an unlikely possibility, a timely psycho-educational intervention can significantly improve the level of autonomy reached by the individual and therefore favorably modify the outcome. Some predictors of long-term outcome are known, primarily childhood intelligence quotient and early language/communication ability, but today this issue is still open. The lack of studies evaluating the long-term effects of the most important intervention programmes should be filled with adequate research. Community support and social integration may be very important in improving outcomes for individuals with autism spectrum disorder. But a real social integration involves a work activity and this is still a great problem today. An adequate and timely preparation of the working career of these individuals is fundamental for their future, and it should be done by choosing, as far as possible, suitable activities for them. Finally, in creating a dignified future for people with autism, we must never forget to listen to their point of view, whenever possible, in order to meet their particular needs.

Keywords: Adolescence, adulthood, autism spectrum disorder, follow-up, long-term outcome, prognostic factors

Öz

Otizm spektrum bozukluğu, çoğu olguda yaşam boyu devam eden bir durumdur ve sıklıkla hastanın ve ailesinin yaşam kalitesini ciddi derecede etkiler. Ancak, günümüzde bu tanı itirazsız son tanı olarak kabul edilmemelidir. Günümüzde, otizm spektrumunun düzelmesi, uzak bir olasılık olmasına rağmen, zamanında yapılacak bir psiko-egitim müdahalesi, kişinin ulaşacağı otonomi düzeyini önemli derecede artırabilir ve bu nedenle, seyri olumlu şekilde değiştirebilir. Uzun vadeli sonuçların bazı öngöstergeleri bilinmektedir (öncelikle çocukluk çağı zeka katsayısı ve erken dil/iletişim becerisi), ama günümüzde bu konu halen karara bağlanmamıştır. En önemli müdahale programlarının uzun vadedeki etkilerini değerlendiren çalışmaların eksikliği, uygun araştırmalarla doldurulmalıdır. Toplum desteği ve sosyal entegrasyon, otizm spektrum bozukluğu olan kişiler için sonuçların iyileştirilmesi açısından çok önemli olabilir. Ancak, gerçek bir sosyal entegrasyon, çalışma faaliyetini içerir ve bu konu halen büyük bir sorundur. İş kariyeri için uygun ve zamanında hazırlık yapılması, bu kişilerin geleceği için esastır ve bu hazırlık, mümkün olduğu kadar kişiye uygun aktivitelerin seçilmesi şeklinde yapılmalıdır. Son olarak, otizmi olan kişiler için saygın bir gelecek yaratırken, onların özel gereksinimlerini karşılayabilmek üzere, kendi bakış açılarının dinlenmesi asla unutulmamalıdır.

Anahtar sözcükler: Ergenlik, erişkinlik, izlem, otizm spektrum bozukluğu, prognostik etmenler, uzun vadeli sonuçlar

Introduction

Autism Spectrum Disorder (ASD) is a mostly lifelong condition characterized by social-communication impairments as well as by repetitive interests and activities (1). Prevalence of ASD has reached 16.8 per 1,000 children aged 8 years and is significantly higher in boys than in girls (2). Etiopathogenesis

of ASD is multifactorial, resulting from complex interactions between genetic and environmental factors (3). Despite the reporting of some possible biomarkers (4), whose validity has yet to be verified, today the diagnosis of ASD is still clinical.

One of the most frequently questions asked by the parents of a child with autism, after the diagnosis has been

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made, is: “what future will my child have?”. This has always been a difficult question, but today it is even more complex than in the past. About 30 years ago, the diagnostic criteria for autism were less inclusive than the current ones, so this diagnosis was usually made to cases that tended to be severe and therefore with a worse prognosis. Today, the increased knowledge of autism has meant that even individuals with a milder symptomatology are now included in the so called “autism spectrum”. Therefore, past studies about the follow-up of ASD can be compared only in part with current ones that consider also less severe cases.

In this narrative review we report an update of the main results of literature about long-term follow-up of individuals with ASD, considering also the issue of early predictors of later outcome. We have preferentially considered the most relevant papers (including also narrative and systematic reviews) on this topic, that have been published in the last 10 years (2008–2018), based on a research carried out through PubMed (United States National Library of Medicine), using in various combinations the following key words: “autism”, “outcome”, “follow-up”, “adolescence”, “adulthood”, “prognostic factors”.

Literature findings

Research and review papers regarding the follow-up of individuals with ASD are countless and very heterogeneous in terms of study methodology and clinical features (autism severity, medical and psychiatric comorbidity, etc.) of the considered samples. Consequently, the results reported in literature are not uniform and highly variable outcomes across studies are reported.

However, according to Volkmar et al. (5), thanks to the earlier diagnosis and more effective, evidence-based interventions, outcomes for people with ASD are gradually improving. Today a growing number of them have a life that is at least partially independent (5). Compared to the past, more people with ASD are able to talk, read, drive a car, graduate from school, and live in the community (6). And it should also be considered that probably independent adults with ASD are numerically underestimated, as many of them have never been diagnosed (5, 6).

But unfortunately, even today most individuals with ASD have not a completely independent life. A percentage of affected adults ranging from 10 to 33% use only simple sentences and have an intelligence quotient (IQ) compatible with an intellectual disability (that is ≤ 70), therefore requiring a “very substantial support” (6) according to the terminology of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (1). Most ASD adults with

intellectual disability have a certain level of autonomy in everyday life, but however they need daily support (6). Only a minority of ASD adults with normal intellectual functioning live in their own home (7). Even today it is rare for adults with ASD to marry or have long-term romantic relationships, as well as the percentage of them with reciprocal friendship is still low (8).

The systematic review of Magiati et al. (9) considered 25 longitudinal follow-up studies in adulthood, finding that social, cognitive and language skills persisted relatively stationary in some studies, while in others even a deterioration over time was described. Adaptive functioning improved in most studies and was better in daily living and communication skill domains than in socialization. Autism or ASD diagnosis was generally stable, although severity of autistic symptoms often improved. Significant language impairments persisted, particularly on the functional and social level (9).

In 2016 Steinhilber et al. (10) performed a systematic review and meta-analysis about the long-term (during adolescence or adulthood) “overall outcome” (that is a global measure of adaptive behavior, considering both social and individual functioning) in people with ASD using a quantitative approach. The authors selected 15 studies including a total of 828 individuals with ASD and found a very good to good outcome in 19.7% of cases, a fair outcome in 31.1%, and a poor to very poor outcome in 47.7%. Therefore, these findings show an unfavorable long-term outcome in almost half of the individuals with ASD.

Today, a growing number of transition-age adults with ASD enroll in a post-secondary academic setting. But unfortunately students with ASD, although they can have a good intellectual functioning, often underachieve academically and present a high incidence of dropping out of school (5). Employment rate is very low for individuals with ASD, lower than people with other disabilities (11): about this aspect, outcomes may improve through a pre-emptive career exploration and a work experience before graduation, besides obviously a careful consideration of job placement (5, 12).

Challenges for people with ASD

According to Volkmar et al. (5), during the transition to adulthood, people with ASD must face several relevant challenges. First of all, there is an increased risk for health problems such as obesity and epilepsy (5). The risk of serious or even fatal accidents is high in these individuals; an increase of premature mortality has been reported particularly in people with lower intellectual functioning and in women, mainly due to neurological disorders and

congenital abnormalities (13–15). Psychiatric comorbidity is frequent, and consequently the use of pharmacological therapies is not rare: there is an increased risk of anxiety (rate range: 22–84%) (16) and depression (rate range: 10–70%) (17); further, possible recurrence of schizophrenia or bipolar disorder was reported (5). Also Attention-Deficit Hyperactivity Disorder (ADHD) is a very frequent psychiatric comorbidity in individuals with ASD (28.2%) (18), and affects the life of children and adults over time impacting negatively on executive functions, peer relations, and mood (6). Substance use disorder has estimated rates of prevalence ranging from 16% to 30% (19, 20), but it is possible that the real prevalence is higher (5). Sexuality issues are frequent, due to the impairment of social understanding (5): obviously, these last situations can also cause serious problems with the law, particularly to those individuals who have never been diagnosed with autism. On the other hand, in adolescents with ASD there is also an increased risk for bullying (in the form of victimization and/or perpetration); in this regard, it should be kept in mind that core symptoms of affected adolescents such as deficits of conversational and social skills lessen their ability to refer bullying incidents (21).

Optimal outcome

For a child with a diagnosis of ASD, the recovery from the autism spectrum, that is the so called “optimal outcome”, is uncommon but not impossible. In 2008 Helt et al. (22), in their review about long-term outcomes, found that 3 to 25% of individuals with ASD no longer met the criteria for this diagnosis; the authors identified a series of early predictors of recovery, including higher IQ, receptive language, verbal and motor imitation, and motor skills, as well as earlier diagnosis and treatment, and (see the classification of DSM-IV-TR) a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified (that is atypical autism) rather than Autistic Disorder (that is “classic” autism). But the recovery from the autism spectrum does not mean that the individual can certainly live in a condition of complete mental health and social adaptation. In fact, after recovery, there are often residual neuro-psychiatric comorbidities, including: depression, phobias, and tics (22). Also ADHD has been reported as a residual psychiatric disorder in individuals with optimal outcome (23). Moreover, after recovery, in the individuals without a clear psychiatric comorbidity, milder difficulties have been reported as concerning social function, pragmatic communication, attention, self-control and emotional maturity (24).

The opinions of stakeholders

Anderson et al. (25) reviewed 17 qualitative studies about the perspectives of individuals with ASD, parents, ser-

vices providers, and other stakeholders in order to find factors influencing negatively or positively the transition outcomes. In our opinion, this work is very important because the point of view of directly involved individuals is often not adequately considered (25). Further, according to Steinhausen et al. (2016), qualitative and quantitative approaches in literature reviewing are not mutually exclusive and even they can be advantageously integrated with each other (10). Anderson et al. (25) identified three barriers for people with ASD, such as: 1) Poor person-environment fit, that is the lacking match between the unique needs of individuals with ASD and the opportunities offered by respective surrounding environments, which is highlighted, for example, when there is an underestimation of the skills of affected people in the workplace; 2) Uncertainty concerning the roles played by parents, many of whom, while wishing their sons to obtain more independence, frequently continue to perform for them daily living tasks; and 3) The lack of adequate services that can help families and individuals with ASD understand and prepare for the transition process. The authors identified respectively also three facilitators: 1) Individualized supports and environmental modifications, thanks, for example, to the presence of supportive people and to management styles using clear communication methods and offering emotional support; also the physical environment should be accommodated considering the sensory abnormalities of people with ASD; 2) Gradual transition to diverse supports (e.g.: vocational services), using various strategies to progressively increase the independence of individuals with ASD from their parents; and 3) Information sharing and collaboration: in this regard, it should be noted the importance for adult service providers of receiving documentation describing the history, needs, and strengths of young adults; at the same time, experiential learning opportunities for young adults, such as attending a college lecture, could reduce their anxiety around transitioning. A key aspect emphasized by the stakeholders was that supports should be focused on the changing aspects of social and physical environment of individuals with ASD rather than their behavior changes (25).

Early predictors of later outcome

According to Magiati et al. (9), childhood IQ and early language/communication (e.g. joint attention) ability resulted to be the most consistent predictors of later outcome, being positively correlated to better adaptive functioning, social skills, and communication. Steinhausen et al. (10) found that the subtype of autism diagnostic category in childhood is a predictive factor for long-term outcome: in fact, a significantly higher proportion of cases with classic autism than cases with autism spectrum disorders (including Asperger syndrome, high-functioning autism, atypi-

cal autism) had a poor to very poor long-term outcome (respectively 61.9 vs. 26.4%) (10). This last result seems to be at least partly predictable. But this point raises an important question: the DSM-5 (2013) (1) eliminated the subdivision into the five diagnostic categories proposed by the DSM-IV-TR (2000) (26), unifying them in the ASD and proposing three severity levels for the affected cases (requiring respectively: support, substantial support, and very substantial support) (1). Could this subdivision into three severity levels be meaningful also in terms of long-term prognosis? An answer to this question still does not exist and adequate studies should be conducted in this regard. In addition, according to Steinhausen et al. (10), whilst the short-term effects of intervention programmes such as Treatment and Education of Autistic and related Communication handicapped CHildren (TEACCH) and Applied Behavior Analysis (ABA) have been well studied, their effects on the long-term outcome are still unknown. Nowadays this lack of information really represents a serious problem.

According to Pickles et al. (27), the greatest gains, even into adulthood, are made by children who have begun to make progress in language and have about average non verbal skills by 3 years of age. In the prospective study of Anderson et al. (7), family's participation in intervention (performed between age 2 and 3) predicted better ASD adult outcomes in the form of increased IQ, achievement, and adaptive skills, and also enhanced the possibility of independence in the individuals with ASD who were cognitively more able. It should however be considered that in this work the adult outcomes were not assessed according to the type of intervention performed, so even from this study it is not possible to infer the long-term effects of interventions such as TEACCH or ABA (7).

The possible effects of the "gender" variable on the adult outcome are still undetermined also because most of the studies include too few women (24). Some studies suggest worse outcomes for ASD women than for men, such as that of Taylor et al. (28) particularly with regard to employment and postsecondary education, while other studies found no significant effects of gender (29).

Finally, the family and environmental factors should not be underestimated. In the large, community-based sample of adolescents and adults with ASD reported by Woodman et al. (30, 31), greater maternal praise (that is the number of positive remarks) was associated in adulthood with better social reciprocity and non-verbal communication, as well as with fewer maladaptive behaviors. Also greater quality mother-child relationships were associated with fewer maladaptive behaviors. Further,

higher inclusion levels in school's academic and social activities were associated with better outcomes with regard to autism symptoms, maladaptive behaviors as well as daily living skills during adulthood (30, 31). In USA Fritzpatrick et al. (32, 33) has studied the stress effects in adults with ASD, finding in them more stressful life events and stress than in the controls; global stress levels were significantly associated with social dysfunctioning.

Discussion

In most cases, autism is a life-long condition, often severely affecting the quality of life of the patient and his/her family, but nowadays this diagnosis should not be considered a final sentence without appeal. Although even today the recovery from the autism spectrum is an unlikely possibility, a timely psycho-educational intervention can significantly improve the level of autonomy reached by the individual and therefore favorably modify the outcome. And the fact that probably many independent adults with ASD have never been diagnosed can distort the results of the studies about the outcome, because these lasts do not include the undiagnosed cases that are likely to be less severe.

Putting aside obvious ethical considerations, ASD undoubtedly represents also a serious economic problem for society, in particular (but not only) because of costs related to the necessary support to not independent adults (6). This is a very important aspect that should not be underestimated, also considering the dramatic increase in the prevalence of ASD recorded in the last decades (2). It would be essential for government authorities to be fully aware that using adequate financial resources for a timely treatment of children with autism constitutes also an investment for the future. In fact, an effective intervention means that a greater percentage of adults with autism will acquire a fair level of autonomy and therefore will require less support. This far-sighted attitude would lead to considerable savings in human and financial energies (as well as in suffering for the individuals with ASD and their families), but unfortunately, even today it is often disregarded.

Often, more than the autism core symptoms (social communication deficits; repetitive interests and activities), there are the heterogeneous conditions that can be associated with ASD to severely impair the quality of life of the affected people and their caregivers: ADHD, anxiety, depression, epilepsy, sleep disorders, and so on. This should be duly taken into account, because for example a pharmacological treatment aimed at these associated conditions can often give favorable results (34, 35).

Today the issue of ASD early predictors of later outcome is still open. In everyday clinical practice, we have known for a long time that, generally, the absence of a medical (e.g.: a rare disease such as tuberous sclerosis) or psychiatric (e.g.: ADHD) comorbidity, an early treatment, as well as the presence, at around 5–6 years age, of a verbal speech (even though atypical) and of a discrete intellectual functioning are all favorable prognostic factors. Unfortunately, nowadays we cannot say much more about early predictors of later outcome. In particular, today's lack of studies evaluating the long-term effects of intervention programmes such as TEACCH and ABA is surprising and should be filled with adequate research.

Regardless of the early predictors mentioned above, as underlined by Magiati et al. (9), community support and social integration may be very important in improving outcomes for individuals with autism (9). But a real social integration involves also a work activity for people with ASD and this is still a great problem today. Very often persons with autism are kept outside the world of work, with the imaginable negative consequences on their self-esteem, although they potentially have the skills to perform tasks of a certain complexity. For this reason, an adequate and timely preparation of the working career of these individuals is fundamental for their future, choosing, as far as possible, suitable activities for them, which for example do not require a direct contact with the public and which are characterized by a certain degree of repetitiveness. Finally, but very important, in creating a dignified future for people with autism, we must never forget to listen to their point of view, whenever possible, in order to meet their particular needs.

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