Autism: psychoeducational intervention

Autismo: intervenções psicoeducacionais

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Abstract

Autism is a long-life disorder that affects not only the autistic child but also the family caregivers. There is increasing recognition about the importance of taking into account both child and family needs when treating autism. However it has been a major debate about what intervention is the most appropriate. In this paper we will review the current literature on the different interventions that have been used in the treatment of autism with special attention to those that are empirically based. It is not our objective to discuss in detail any particular intervention. We intend to present an overview of both positive aspects and limitations of each type of intervention. The conclusion is that there is no single approach that is totally effective for all children the whole time. Instead, it is argued that families change their expectation and values regarding their children's treatment according to the child's development and the family context. In other words, a specific intervention that may work well in a certain period of time (e.g. pre-school years) may not work so well in the following years (e.g. adolescence). Finally the importance of early identification and treatment of autism is stressed.

Keywords: Autistic disorder/therapy; Disease management; Family/complications; Identification (Psychology); Early intervention (Education)

Resumo

O autismo é um transtorno permanente que afeta não somente a criança autista mas também a família que cuida dela. Há um crescente reconhecimento sobre a importância do tratamento do autismo envolver tanto as necessidades da criança como as da família. No entanto, há controvérsias sobre qual intervenção seria a mais apropriada. Neste artigo, revisaremos a literatura recente sobre as diferentes intervenções que têm sido utilizadas no tratamento do autismo com ênfase naquelas que possuem base empírica. Não pretendemos discutir em detalhe nenhuma intervenção em particular, mas apresentar uma visão geral sobre os aspectos positivos e as limitações de cada tipo de intervenção. Concluímos que não há uma abordagem única que seja totalmente eficaz para todas as crianças durante todo o tempo. Ao contrário, argumentamos que as famílias modificam suas expectativas e valores com relação ao tratamento de seus filhos de acordo com a fase de desenvolvimento da criança e do contexto familiar. Em outras palavras, um tipo específico de intervenção pode funcionar bem por um certo período (e.g., nos anos anteriores à escolarização) e não funcionar tão bem nos anos subseqüentes (e.g., adolescência). Finalmente, enfatiza-se a importância do diagnóstico e tratamento precoces do autismo.

Descritores: Transtorno autístico/terapia; Manejo clínico, Família/complicações; Identificação (Psicologia); Intervenção precoce (educação)

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Introduction

Currently, autism is classified as a pervasive developmental disorder that encompasses severe lifelong difficulties in social and communicative skills - beyond those accounted for by general delay – and also restricted/repetitive behaviors and interests.[1] Both diagnostic frameworks mostly used (ICD-10/ WHO and DSM-IV/APA) require the identification of abnormalities in those areas of development prior to the age of 36 months. In fact, accounts of parent's worries regarding their children's social behavior and play begin in the first two years of life.[2-3] However, the pattern of development may change according to the degree of cognitive impairment being worse in those whose IQ is below 50 .[4] Those who have severe cognitive impairment are unlikely to develop speech and likely to develop self-injury behaviors, requiring life-long care. In general, most individuals tend to improve with age when under appropriated care. Nevertheless, despite these possible improvement communication, social problems tend to be life-long. The studies reviewing prognosis and outcome in autism show that the best predictors of both overall social functioning and school performance are the child's cognitive level; degree of language impairment and development of adaptative skills such as self care.[5] Thus, parents when deciding for a certain type of intervention must bear in mind that to date, there is no good evidence that a particular treatment may cure autism and also that different treatments have a specific impact on each children. This impact depends on the child's age, degree of cognitive impairment, the presence or not of speech and the severity of general symptoms. It is important to be aware that most autistic children do not show deficits in all developmental areas and many have one or more dysfunctional behaviors for brief periods of time or in particular situations. In addition, other aspects, such as family functioning, social support, etc, are also important.[4]

Intervention: multiple approaches

There are claims that the treatment planning should be structured according to the patient's life stages.[6] Thus, with young children the priorities should be speech and language therapy, special education and parent support. On the other hand, with adolescents, social skills group, occupational therapy and sexuality issues should be focused. In adulthood, housing options and guardianship issues should be focused. Unfortunately, there are few options of housing in our country – an area that has been largely neglected, raising concerns for parents.

Attention has been called to the variety of services available. There are services based on individual approaches by trained professionals from a particular area, in contrast to multidisciplinary clinics[7] It was stressed that, the effectiveness of the treatment depends on the experience and knowledge of the professionals about autism and mostly, their ability to work together in a team and with the family. One of the most stressful situations for the parents when dealing with professionals is the controversy surrounding the diagnosis process. There are authors who complain about contradictions among the staff regarding either the diagnosis itself or treatment referral. These authors also highlight four basic aims for any treatment goals: 1) fostering social and communicative development; 2) enhancing learning and problem-solving; 3) decreasing behaviors that interfere with learning and access to opportunities for ordinary experiences; and 4) helping families to cope with autism. These goals will be further discussed.

1. Fostering social and communicative development

Children who are very impaired in their ability to communicate verbally may require some form of alternative communication. The appropriate choice of system depends on the child's skills and degree of impairment. Sign systems have been widely used in these cases such as the. Makaton system, which incorporates symbols as well as signs. This resource is largely used in the UK although the evidence of significant improvement in communication of autistic children is limited.[7]

A pictorially based system seems to pose least demands on cognitive, linguistic or memory skills since the pictures or photos reflect the individual needs and/or interest. The PECS (Picture Exchange Communication System) is an example about how a child can take an active role by using Velcro or stickers to indicate the beginning, changes or ends of activities.[8] This system facilitates both communication and understanding once the association between the activity/symbols is established.[9] In contrast with parent's worries about the danger that signs and photos decrease motivation for the development of speech, so far there is no evidence that this may occur. In fact, it is noted that by focusing on alternative forms of communication the children may be encouraged to use speech.[10] At the same time, it was found that the signing of autistic children follow the same pattern of that found for verbal training programmes, that is, signs are rarely used to share experiences, to express feelings/emotions or to communicate reciprocally.[11] For younger children, who are able to use some words or sounds spontaneously, individualized language programmes are important for improving comprehension and the complexity of speech. Attention was called for the need of parents using effective and consistent strategies to encourage speech and develop imaginative skills.[12] For example, parents can keep toys and biscuits away from the child but at their sight using transparent containers, which attract the child's attention. This simple strategy helps the child to need to communicate with adults in order to have what he/she wants. Imaginative skills may be encouraged by, for example, focusing on the child's stereotypes rather than just eliminating them.

The technique known as "Facilitated communication", involves the use of physical support to hands, arms or wrist to help children to use communication boards of various types, thus improving language skills. However, there are evidences that the responses are mostly under the control of the facilitator rather than of the child.[13-14]

Computerized communicative devices have been specially designed for children with autism. In general, the focus is on turn taking and interaction. Interchangeable keyboards of increasing complexity make it possible for children to progress gradually from a single-symbol board to the independent use of multi-symbol displays, which are personally tailored to the individual's environment, needs or interests. Another issue in favor of the use of computers is that visual material is best understood and accepted than the verbal one. However, it should be warned that computers may also increase "obsessions" for technology.[12]

Another visually based instructional system is the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) educational programme.[15] It is a highly structured programme that combines different visual materials to improve language, learning and to reduce inappropriate behaviors. Differently colored areas and containers are used to instruct the child about, for example,

the appropriate place for them in a certain moment and the correspondent sequence of activities throughout the school day. The basic components are adapted to suit the child's individual needs and developmental profile assessed with the PEP-R (Psychoeducational Profile-Revised).[16]

Even children with no apparent language difficulties may also require some augmentative communication systems in some situations. Most autistic children have difficulties in understanding abstract language or dealing with a complex sequence of instructions that need to be broken down into smaller units. For example, in a classroom the students were encouraged by the teacher to complete a story about a girl and her dog. Each student was invited to verbally build a little part of the story. After some boys have made their contribution focusing into the girl's thoughts, feelings and activities, the autistic student suddenly concentrated in the dog, changing the topic of the story and without making a connection with the previous parts. In similar cases, a board with drawings showing the sequence of situations might be helpful. Another young autistic boy did not react to the command "clear up the toys" but did so when asked to "put the toys on the basket" or look at the picture with this instruction.

Metaphors should either be avoided or fully explained otherwise they may cause much distress, as in sentences such as "I will die if I do not have lunch now". Questions should be as simple and concise as possible, trying to reduce ambiguity. Thus, it should be better to ask "what is your mother mobile phone?" than "can you give me your mother's mobile phone please?". For this last question the autistic child may answer "yes" and do not make any further action or understand that he should give the mobile (the machine) to the person. Immediate echolalia is the repetition of what somebody has just said whilst remote or delayed echolalia are words, phrases or even dialogues borrowed from other people or from the media.[10] A wide vocabulary, borrowed from adults, for example, may be perceived as a sign of linguistic competence rather then stereotyped language and this fact may delay the real diagnosis. Other special characteristics of language in autism are reversing pronouns, as in the "I-you" confusion, and repetitive questioning. These behaviors reflects children difficulties about developing a sense of self and of "others", the ability to communicate socially and to deal with unpredictable situations. Thus, the fact that a child may keep asking repeatedly what she's going to do at Christmas from the beginning of the year may be a reflect of his or her anxiety about upcoming events. An incessant questioning about a person's height or weight may relate to the need of being sociable without having the appropriate tools which would help in the understanding about other people's mind.

A recent approach to social difficulties is a training package designed to improve the ability to mind-read.[17] Again, although there are some evidences of improvement, generalization is poor.

2. Enhancing learning and problem-solving

It seems to exist a direct relationship between time spent in a classroom, working on an academic subject, and the improvement achieved in that subject.[18] That better academic attainment is significantly associated with verbal intelligence although the performance is below the child's chronological level.[5]

A common question has been whether an autistic child should attend a special school for autistic children specialized in broad learning difficulties or being integrated into the mainstream school. So far there is no final answer to this question as there is no well-controlled comparative study concerning the levels of integration in these systems. It seems that each case should be individually treated, focusing on the child's needs and strengths. It is important to bear in mind the advantages of being exposed to non-handicapped children and learning from them by imitation but not forgetting that they will be at risk for bulling by other children.[12] Anyway, some studies suggest that with appropriate education more autistic children may use their intellectual skills that they have to achieve functional academics.

As mentioned before, studies about teaching programmes such as TEACCH show the importance of environmental organization, the use of visual clues and the work based on the child's previous skills rather then trying to overcome the main deficits of autism. Kanner, in 1943, provided one of the first descriptions of the benefits of this sort of work in the case of Donald.[19] The health visitor's reports show how surprised she was with his progress when he moved away to a farm and attended a school nearby. She noted that the teacher used to deal properly with his bizarre behavior and the farmers have taken advantage of his obsessional behaviors making them much more functional, for example, his obsession for numbers was used in activites where measures were needed in the farm area.

There is evidence that early educational provision, since 2 to 4 years, combined with the integration of all professionals is the most effective therapeutic approach.[20] It seems that this context facilitates consistent management techniques, which in turn may be related to the generalization and maintenance of acquired behaviors. These strategies help to minimize or avoid subsequent behavioral problems as the children quickly learn that their behaviors may serve as a mean to control the environment.

Another approach that has some empirical base is the Lovaas' method.[21] It is an intensive behavioral programme, in general conducted at child's home with at least 20 hours of educational work per week. Different developmental areas such as language, cognitive aspects and social behavior are target. One of its limitations is that it imposes some restrictions to the families such as determining the hours when family members must be available and committed to the programmes, perhaps giving up planes such as a pregnancy, new post at job, etc. Traditional behavior therapy such as the ABA approach to the analysis of behavior also appears to be helpful. The main assumption is that the behavior can be understood by the identification of the antecedents and consequences of a certain behavior. However, attention has been called to the fact that it is very difficult to take into account the behavior as perceived by the child, making possible to explain a certain behavior by other that preceded it or not.[12]

3. Decreasing behaviors that interfere with learning and access to opportunities for normal experiences

Attention has been called to the "function" of challenging behaviors, that is, the underlying causes of behavioral disturbances (e.g. aggressive, self-injurious) and its relationship with language and social impairment.[12] Obsessional symptoms also help to maintain these behaviors. There are authors who point out that intervention techniques should focus on the improvement of developmental areas, mainly social skills and language, rather than on the elimination of problems.

Some studies have demonstrated that challenging behaviors serve as an important communicative function[22-23] which are: to indicate need for help or attention; to escape from stressful situations or activities; to obtain desired objects; to protest against unwanted events/activities; to obtain stimulation. The knowledge that challenging behaviors are a way to communicate also allows people to respond better to these behaviors because they know that they were elicited due to poor communication and are not deliberate acts of aggression. There are approaches that can help to reduce these behaviors by helping the child to use alternative means of communication. In fact, most studies investigating the efficacy of these approaches show decreasing of these behaviors when the appropriated technique is used, which is, the identification of the underlying function of the behaviors. However, it should be noted that most of these are studies using small samples or single-case design, multiple baseline or Applied Behavioral Analysis (ABA) type design. Very few are randomized treatment trials which would allow a wider and more accurate interpretation of the results. One limitation of these approaches is that idiosyncratic or multifunction causes of these behaviors cannot always be identified.[12,24]

There are authors that emphasize how important it is not to encourage or tolerate behaviors that will later be perceived by others as inappropriate. In this case, problems arise not due to the nature of the behavior but because of changes in other people's attitudes.[12] For example, touching adult's certain parts of the body (e.g. breasts) may be view as positive when the children are young (e.g. interest in people) but become a problem as they grow older. Some types of obsessive compulsive behavior (e.g. "collection" of cartoon characters) may be intensively encouraged by parents and relatives at one moment but cause trouble and be condemned later on. Of course it does not mean that these activities should be forbidden. They should not be too much encouraged as they may escalate and interfere in the learning process if not brought under control. Without careful planning, children may replace rituals and obsession with behaviors that are even more disruptive.

It is important to highlight that the modification of challenging behaviors shall be made gradually with the reduction of anxiety and distress being the main goal. There are some helpful guidelines, which include the establishment of clear and consistent rules (when the behavior is not allowed or permitted), graduation of change; identification of underlying functions such as anxiety or uncertainty; environmental modifications (e.g. change in attitudes or turning the situation more predictable) and turning the obsessions into productive activities.[12]

Regarding social behavior, in children who are more severely handicapped, inappropriate behaviors such as screaming, undressing or masturbating in public may be a great source of concern. On the other hand, children less handicapped have, as the source of concern, difficulties in empathy, social understanding and reciprocal interactions that seem to be the core deficits in autism. This social impairment can be better explained by deficits, in theory of mind, that are, the ability to understand other people's beliefs, thoughts or feelings.[25] Although setting clear rules to deal with these difficulties is helpful[26] knowing how to make friends, understanding other peoples 's feelings and thinking are not rule- based skills that are acquired through teaching. It seems that social skills training is more effective when conducted in a particular situation, as each situation demands a different social response. Isolating social skills groups tend to be a more limited procedure due to the child's difficulties with generalization of the acquired skills.

Learning how to interact with children of the same age is a demanding task for autistic children. There have been some studies with intervention designs that range from constant input of teachers to free-play groups that involve children with typical development. Again, with the different designed interventions although there were improvements in the frequency of interaction it was difficult to maintain peers' co-operation for longer periods of time.[27] Anyway, the interaction lacks reciprocity as the non-handicapped children have to adapt their behavior to the autistic children according to the principals of somebody else (e.g. teacher). Offering opportunities (e.g. swimming pool, playground) for the children to observe or interact spontaneously (although with limitation) with other children seems to be a good strategy.

4. Helping families to cope with autism

There is evidence that autism has some impact over the family and that the burden of care falls largely upon the mothers.[28]

One study compared the stress profiles of mothers and fathers of children with autism.[29] The results were that mothers of autistic children showed more stress than fathers, suggested that this result was a consequence of different responsibilities assigned to child rearing for each parent.

Another study showed that mothers of children with autism also showed more depression than mothers of Down Syndrome children suggesting that the burden of caring and the nature of child's handicap play a part in maternal depression.[30]

A study investigating the role of perceived parenting stress and parental depression on marital intimacy between parents of handicapped children showed a similar result.[31] Results indicated that mothers of children with autism showed significantly higher stress and depression, in addition to lower marital intimacy than mothers of typically developing children and mothers of Down syndrome children.

It was demonstrated that parents are most stressed by delays in getting a diagnosis,[2] by disabilities associated with autism itself (e.g. lack of speech, hyperactivity and tantrum behaviors) and by worries about the future condition of their child.[32] The identification of parental concerns and the provision of support are crucial because parental stress may affect the child's development.

One study[33] showed that mothers of the autistic children have higher scores in most of the General Health Questionaire GHQ dimensions, compared to the mothers of children with learning difficulties and typically developing children. .[32,34-35] It is worth noting that, in this study, obstetric hazards occurred in the majority of mothers of both clinical groups suggesting that maternal worries started before the child's birth. These concerns gave place to real demands as developmental problems were identified by the child's birth for the learning disabilities group and for the autistic group within the first two years. The impact of the stressor on the family may be increased if there is accumulation of preexisting or simultaneous demands on the family unit.[36] It is stated that the demands upon families fall into five categories: illness of a family member which can be accompanied by financial needs, increased strains due to care giving and/or uncertainty surrounding the diagnosis, treatment and prognosis; normative transitions which can coincide with the stressor; prior strains that can

be exacerbated; extended working hours to meet financial needs and intra-family and social ambiguity due to lack of social and community guidelines.

In addition, in that study, the majority of mothers of the clinical groups did not work a condition that may increase the burden and social isolation. In fact, some mothers gave up their careers to look after the child. Sleep problems were identified in the children of both clinical groups such as difficulties to go to sleep and frequent waking and restless. Mothers of children with sleeping disorders showed higher scores in the anxiety/insomnia than mothers of children not with sleeping disorders suggesting that mothers are affected by their child's sleeping problems. It was called attention for the role of family routines, in particular bedtime routines for children to prevent parental stress and lack of couple intimacy.[36] It also has been stressed the risk of piling up stressors for parents health and the the role of social support and quality of the health systems in buffering the effect of stress upon parents. Social support is an important resource to the family and has been viewed as one of the key stress buffering factors in families under stress. The information exchanged at the interpersonal level provides emotional support, esteem support and feelings of belonging to a network of communication with mutual understanding. The authors claim that professionals working with these families can help them to assess both stresses and resources in order to solve problems. Families can be helped to be more resilient in the face of change by restructuring roles, rules, patterns of interaction, boundaries and outside relationships with the community. Appraisal may also play a part as it refers to the families' set of beliefs and assumptions about their relationship to each other and also about the community and systems beyond their boundaries.[37]

In that study, mothers also reported how helpful it was having support, at home, about the management of the child's behavioral problems, and in particular those associated with everyday tasks.[38] It has been shown that the maternal feelings of self-efficacy when rearing their child were affected by stress.[39] One of the most important issues when developing support groups for parents is to bear in mind that families vary in the sort of support and information they are in need. Even within a family, each member may have different views and expectation about the child and their needs. It was pointed out that is not enough to say to parents what they should do but to show them how to do.[7] Also important is to help parents and siblings to recognize the frustration and anger and the ambivalence of their feelings as a normal process of adaptation. Teaching management techniques and providing information about the condition is as important as focusing on emotional aspects.

Attention was also called about the importance of advising parents about the advantages and disadvantages regarding different treatments.[12] Although it is important not to appear so much pessimistic there is also the need to show that treatments differ in their rationale and that systematic evaluations have yet to be demonstrated for the majority of them. Consequently, their value remains uncertain.

5. The importance of early diagnosis

Diagnosis during the pre-schools years is still very rare, despite the claims that early intervention is the best procedure for child's development.[40] This is in part due to a lack of knowledge about the typical development of a child, in particular in the area of non-verbal communication being impairment in joint attention abilities the most significant marker. The most common situation is that the worries of parents and professionals lie on child's speech delay rather then on the social aspects of behavior.

Accurate diagnosis is not an easy task for professional as there can be problems in distinguishing between children with autism and non-verbal children with learning disabilities or language impairment. However, by the age of 3 years, children tend to meet autism diagnostic criteria on a variety of diagnostic measures.[41] In fact, there have been research efforts on the development and validation of autism-specific screening instruments for use with young children.[42] There are currently several instruments to be used with children in different stages of life such as the Checklist for Autism in Toddlers (CHAT), Pervasive Developmental Disorders Screening Test (PDDST); Screening Tool for Autism in two year old; Checklist for Autism in toddlers-23 (CHAT-23) and the Modified Checklist for Autism in Toddlers (M-CHAT). Unnecessary delays in diagnosis have important practical implications as the development of effective although simple communication strategies at an early stage of life help to prevent disruptive behavior.[12]

It was mentioned before that the best predictor of the subsequent development are both the level of communication and cognitive abilities developed during the pre-school years.[7] Thus, there are enough reasons to increase efforts in identification and intervention for young children with autism as early as possible. Practical guidelines for health professionals in the community to reach this goal have been the focus of some studies.[38,43]

Summary & recommendations

When facing a diagnosis of pervasive developmental disorder, all families wonder what type of psychoeducational intervention is the most effective. The answer is not so straightforward as it appears, despite the large amount of treatments that have been advertised. By reviewing the current literature on the different interventions that have been used in the treatment of autism we concluded that few are empirically based. Although some sort of improvement can be demonstrated in different studies, the results should be interpreted with caution as well-controlled studies are very rare. Apparently there are no single approaches that are totally effective for all children, along the different stages of life. That is, a specific intervention that may work well in a certain period of time (e.g. pre-school years) may show a different picture in the following years (e.g. adolescence). This occurs in part because families change their expectation and values regarding their children's treatment according to the child's development and the family context. On the other hand, a point of consensus in the literature is the importance of early identification of autism and early intervention and their relationship with subsequent development. Finally, another issue to bear in mind is the need to focus on the whole family rather then only on the individual with pervasive developmental disorder.

*Bosa, Callias, in press.

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