Editorial

Childhood autism: The good, the bad and the ugly

Sri Lanka Journal of Child Health, 2018; **47**(2): 97-99
DOI: http://dx.doi.org/10.4038/sljch.v47i2.8472
(Key words: Childhood autism)

The word 'autism' first took its modern connotations as far back as 1938 when Hans Asperger of the Vienna University Hospital adopted Bleuler's terminology *autistic psychopaths* in a lecture in German about child psychology[1]. It is now known that autism is a neuro-developmental disorder characterized by disturbances in social interaction and communication in multiple contexts together with restricted interests and repetitive behaviour patterns. Autism is one of the neuro-developmental disorders that has increased in numbers over the last decade due to still unknown reasons. Though parents generally observe signs in the first two or three years of their child's life, sibling studies report most subtle signs to be evident in children even as young as 6 months of age. The signs tend to develop gradually. While some parents report that their children reached developmental milestones at a normal pace and then deteriorated, most evidence support an on-going decline in developmental progression.

It is estimated to affect around one per cent of all children and they have marked speech, language and communication needs[2]. It is also being recognised that the entire malady is of a heterogeneous range and is best described by the terminology *Autism Spectrum Disorder* (ASD). Any given child, on careful evaluation, could be placed in a position within the range, extending from mild involvement to a disturbance of very marked severity. The current terminology of ASD, in a more simplified attempt, encompasses the previous diagnoses of autism, Asperger syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS) and childhood disintegrative disorder. The real cause of the autism spectrum is not known and risk factors include having an older parent, a family history of the condition and certain genetic conditions[3].

The diagnosis is exclusively based on symptoms and the presenting profile. Treatment efforts are generally individualized to each affected child and it is important to realize the truth of the notion that 'no size fits all'. The cardinal internationally accepted and scientifically proven therapy for ASD is intensive intervention based on communication and behavioural principles that will result in improvement of the presenting clinical features. Medications may need to be used to try and improve certain associated problems but is not a curative option.

It is universally recognised that very often the diagnosis is unnecessarily delayed. There is a tendency amongst those who provide healthcare to children to disregard or attach minimal significance to some of the tell-tale symptoms and signs observed and reported by parents. There is an inclination to label them as at extreme ends of normality and to await normal progress with time. This is particularly evident when the symptoms and signs are rather subtle and would be obvious only to those who are specifically trained in the diagnosis and management of ASD. Delays in the diagnosis with the inevitably consequent deferment of the commencement of necessary interventions are now recognised as avoidable obstacles in a quest towards appropriate and optimal management of these children. Up to now, there has only been anecdotal evidence to support the concept of early diagnosis and prompt initiation of the ideal management strategies in a determined effort towards securing the best possible outcomes. However three studies over the last decade have provided incontrovertible proof that such notions have scientific validity now.

The first, a randomized controlled intervention study published in 2006, provided promising data on the use of joint attention and play interventions for young children aged 3 and 4 years with autism[4]. The authors went on to say that future studies need to examine the long-term effects of these early interventions on affected children's development. The second study, documented in 2016, clearly showed that in a long-term follow-up of a randomised controlled trial on parent-mediated social communication therapy for young children with autism (PACT) study, on children 2 to 4 years old with core autism, the results were the first to show long-term symptom reduction after early intervention in autism spectrum disorder[5]. The data supported the clinical value of the PACT intervention and the outcomes have implications for management of affected children.

The third study was quite unique. It was published in 2017 and the protocol assessed the data in a randomised trial of a parent-mediated intervention for infants at high risk for autism. The final assessment was the longitudinal outcomes up to the

age of 3 years. They recruited a high-risk group of infants with a familial risk of autism[6]. This very first randomized controlled trial of a very early social communication intervention for infants at familial risk of developing autism and followed up for 3 years has shown a treatment effect, extending to 24 months after the intervention ended, to reduce the overall severity of autism prodromal symptoms and enhance parent–child social communication over this period.

There are only a few meta-analyses published on autism interventions and those are still inconclusive due to smaller numbers and heterogeneity in the age groups studied[7]. However, the results definitely support parent mediated interventions. The down side of these parent mediated interventions is the possible stress on the families due to the demands made on their time and energy to carry out the management protocols. Therefore the latest recommendations by the World Health Organisation, together with experts in autism, are based on parent-child interactions in the natural environments to enhance social communication through play.

These well recognized and scientifically proven interventions have now been firmly established to produce results when instituted very early. As a corollary, these also underline the importance of early diagnosis for a successful outcome. There are other interventions like Sensory Integration Therapy (SIT) which uses play activities in ways designed to change how the brain reacts to touch, sound, sight and movement. These are popular and have shown some results but they are rather tedious to perform and need experts to carry them out. Apart from all that, in a systematic review of research involving sensory integration therapy for autism, out of 25 studies, three had positive results but serious methodological flaws were found across all studies. The authors concluded that the evidence-base does not support the use of SIT in the treatment of autism[8].

There are other reports of extravagant claims made for cannabis (marijuana) in various forms as a treatment for ASD. However, there is no robust scientific evidence for using this therapy routinely. A more recent management strategy that has been intensively promoted for ASD is stem cell therapy[9,10]. The published papers have grave methodological failings and confounding factors. There are some serious undesirable effects of this form of treatment as well. To compound matters further, there are no properly conducted randomized clinical trials on this form of therapy. Much of this work has been done in India but a Consensus Statement of the Indian Academy of Pediatrics on Evaluation and Management of Autism Spectrum Disorder[11] does not even mention stem cell therapy by name. Furthermore, it very clearly states that as far as complementary and alternative therapies are concerned, there is no evidence for effectiveness of these therapies and paediatricians should be able to counsel caregivers to not opt for these therapies. It is presumed that these 'alternative therapies' include the stem cell treatment modalities as well.

As for the situation in Sri Lanka, there have been commercially motivated attempts to advertise stem cell therapy for autism in India by some interested parties. These developments have prompted the Sri Lanka College of Paediatricians to issue a strongly worded Press Statement[12] against the use of this therapy of unproven efficacy. The Press Statement concludes with the declaration "*Stem cell therapy for these conditions is only used at the experimental level at research laboratories and is currently* ***NOT*** *recommended to be used for any of the Neuro-Developmental Disorders including Autism Spectrum Disorder. This is simply because positive outcomes from stem cell therapy have not been scientifically proven internationally from several well conducted research studies. Also it is not licensed to be used in Sri Lanka by the Medicinal and Health Control Authorities of Sri Lanka. Therefore the public is hereby warned not to become prey to these parties who extol the virtues of unproven therapies and who are likely to exploit them and their families*."

Stem cell therapy is very expensive, especially when the subjects have to travel to another country to get it. In view of currently available scientific evidence, it is almost like the proverbial straw to a drowning person. Local and foreign commercial interests taking advantage of the heart-breaking agony suffered by the parents of affected children is best described as perhaps the unpleasant and uglier side of the current situation that is prevalent in Childhood Autism Spectrum Disorder in Sri Lanka.

References

1. Asperger H. *"Das psychisch abnormale Kind" [The psychically abnormal child]. Wien Klin Wochenschr* (in German). 1938; **51**:1314–17.

2. Beard A. Speech, language and communication: a public health issue across the lifecourse. Paediatrics and Child Health 2018; **28**(3)126-31. https://doi.org/10.1016/j.paed.2017.12.004

3. Autism Spectrum Disorder. Available from:

https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml#part_145441. Accessed on 16th April 2018.

4. Kasari C, Freeman S, Paparella T. Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. *Journal of Child Psychology and Psychiatry* 2006; **47**(6):611–20. https://doi.org/10.1111/j.14697610.2005.01567.x PMid: 16712638

5. Pickles A, Le Couteur A, Leadbitter K, *et al*. Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *Lancet* 2016; **388**: 2501–9. https://doi.org/10.1016/S01406736(16)31229-6

6. Green J, Pickles A, Pasco G, *et al*. Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *The Journal of Child Psychology and Psychiatry* 2017; **58**(12):1330-40. https://doi.org/10.1111/jcpp.12728 PMid: 28393350 PMCid: PMC5724485

7. Nevill RE, Lecavalier L, Stratis EA. Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. *Autism* 2018; **22**(2):84-98. https://doi.org/10.1177/1362361316677838 PMid: 29490483

8. Lang R, O'Reilly M, Healy O, *et al*. Sensory integration therapy for autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders* 2012; **6**(3):1004-18. https://doi.org/10.1016/j.rasd.2012.01.006

9. Sharma A, Gokulchandran N, Hemangi Sane H, et al. Autologous Bone Marrow Mononuclear Cell Therapy for Autism: An Open Label Proof of Concept Study. *Stem Cells International* Volume 2013. ArticleID623875,13pages

10. Sharma AK, Sane H, Gokulchandran N, *et al*. The need to review the existing guidelines and proposed regulations for stem cell therapy in India based on published scientific facts, patient requirements, national priorities and global trends. *Indian Journal of Stem Cell Therapy* 2015; **1**(1):7-20.

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The author declares that there are no conflicts of interest.

The author wishes to acknowledge the support extended by Dr. Samanmali P. Sumanasena, Senior Lecturer & Honorary Consultant Paediatrician, Disability Studies Department, Faculty of Medicine, University of Kelaniya, Sri Lanka, in providing some of the literature on the subject and for critical evaluation of this editorial.