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Introductory Chapter: Controversial Issues in Autism - Research and Practice

Michael Fitzgerald

1. Introduction

The major reason why there are so many controversial issues in autism is because it is such a heterogeneous condition. There are no sub-types of autism at this time, despite almost fifty years of searching for them. This quest continues but there is doubt whether it will succeed. There are no diagnostic biomarkers in autism or indeed, in psychiatry as a whole. This in a way, is what distinguishes psychiatric diagnoses from medical diagnoses like diabetes. Of course, there are many conditions associated with autism like tuberous sclerosis, but that is quite a different matter to having a biomarker specifically for autism. There is also a great deal of heterogeneity in relation to aetiological factors. There are a large amount of genes involved of small effect, associated with autism and the number is continually increasing, but there is no specific pattern of genetic findings for autism and unlikely to be again because of heterogeneity. We need new research paradigms for research in psychiatry. The medical model will not suffice.

2. Heterogeneous issues in autism

2.1 Validity

Validity is probably the biggest problem in psychological and psychiatric research on autism. Validity of diagnostic categories is probably the weakest link in research in this area.

2.2 Screening and diagnosis in autism

Charman and Gotham [1] state that, 'we're limited by the lack of a true test for autism spectrum disorder'. the same goes for screening instruments. One of the most widely used screening incidents, the M-CHAT [2] (modified checklist) according to Peter Hess [3], 'misses a majority of autistic children at eighteen months, and this failure was particularly in those with average IQ'. Hackethal [4] stated that the M-CHAT, 'misses the majority of children with ASD'. In terms of diagnostic instruments for autism, Charman and Gotham [1] state correctly that, 'expensive ASD-specific diagnostic instruments will not always be appropriate'. Indeed, NICE [5] recommend no specific instrument for clinical diagnosis and state that clinical diagnosis of autism should be done by a clinical expert in autism, which usually will mean a psychiatrist, psychologist or specialist paediatrician. Charman and Gotham [1] state that, 'professionals must be realistic about

the limitations of diagnostic instruments: ultimately, these measures cannot solve a difficult diagnostic decision, and they may not be universally necessary. Experienced clinical judgement is essential for a correct diagnosis'. This would be in line with the NICE [5] Guidelines. The ADI-R (Autistic Diagnostic Instrument Revised) [6] and ADOS (Autism Diagnostic Observation Scale) [6] criteria to define autism are very narrow concepts of the disorder. I see many parents who come to me in great distress knowing that their child has autism and that the school also observed this, but having been told that their child did not have autism according to the ADI-R. This instrument is not appropriate to making a sole diagnosis of autism in clinical practice. It not uncommonly misses high functioning autism. In addition, Ventola et al., [7] have shown that the ADI-R was significantly under-diagnosing toddlers. How biased and unrepresentative the patients in this survey can be seen by Professor Gillian Baird's work [8] on autism in the general population. Indeed, using these narrow criteria gives a prevalence of autism of 25 per 10,000. When you use the broader autism spectrum, you get a truer rate of 116 per 10,000. One of the problems also is that the National Institute for Health Care Excellence, [5] Guidelines on the diagnosis of autism which are accepted throughout the world, are not followed. Professor Dorothy Bishop, Professor of Developmental Neuropsychology at the University of Cambridge told Adam Feinstein, [9] that, 'if it could be shown that there were real benefits in accuracy of diagnosis from adopting this lengthy procedure, then I would be happy to say 'okay', but the originators of the instrument have never demonstrated this – it is more an article of faith with them' [9].

The problems with different criteria for diagnosis was demonstrated by Fitzgerald et al., [10] from a sample of 309 persons referred with, 'autistic tendencies', found that 272 met criteria for autism on the Autistic Disorder Diagnostic Check List by Lorna Wing [11] which was the predecessor of the DISCO (Diagnostic Interview for Social Communication). 144 met ICD 10 criteria [10]. Kanner and Eisenberg, [12] five criteria gave a number of 24 with autism while Kanner and Eisenberg's two criteria gave a diagnosis of 220 [10].

Steven Hayman, former Director of The National Institute of Mental Health in the United States stated that the diagnostic and statistical manual enterprise was, totally wrong... an absolute scientific nightmare. Many people who got one diagnosis, got five diagnoses, but they don't have five diseases – they have one underlying condition', [12]. Insel [12] said that the psychiatric diagnosis, 'have no reality. They are just constructs', and he wanted a, 'diagnostic system based upon biological foundations'. While females with autism are more likely to be missed, there is the paradox that women are more likely to be given a psychiatric diagnosis with less physical tests done on them, then males and more physical diagnosis to be missed [13]. ASD diagnosis, 'lacks biological and construct validity' [14].

Replication of research findings in autism is and continues to be quite a problem. Replication is central to our understanding of science. Indeed, we usually require multiple replications before we would feel that a finding is secure. Ioannidis [15] stated that, 'there is increasing concern that most current published research findings are false'. There are problems with study power, sample size, data mining and hypothesis being tested at the end of a study which weren't there in the beginning. Bottema-Bentel et al. [16] studied autism treatment studies in one hundred and fifty papers and found that only 6% of them with genuine conflicts of interest admitted to them in the original paper and could not complete their statistical analysis on these papers because there was insufficient numbers of high quality papers. The authors of this paper were equally concerned about the lack of mention of adverse events, and only 7% of the one hundred and fifty studies examined adverse events [16].

The publication of only positive findings and the more important point, the non-publication of negative findings has been a serious journal problem for a long time. In science, negative findings are as important as positive findings.

2.3 Psychology of autism

There are problems with TOM (problems with theory of understanding other peoples' minds) and autism. TOM deficits have been a dominant theory of autism for many decades. It is mentioned endlessly by psychologists and psychiatrists and has been presented as a, 'fact'. The situation is much more complicated. It is not as universal as the theory proponents have suggested and there is considerable non-replication. This has been reviewed by Gernsbacher and Yergeau [17]. They pointed out that this stereotyping has been particularly damaging for persons with autism. It has stigmatised them. The neurodiversity movement has challenged this stigma [18]. The deficit in TOM undermines persons with autism's independence, truthfulness and trustworthiness and makes them unsuitable for many jobs. This is unhelpful and isolates them and leads to further social exclusion.

2.4 Vaccines and autism

The false association between the MMR vaccine and autism has been by far, the most damaging research carried out in this area. It was published in a prestigious journal, The Lancet [19]. It led to a crisis in vaccination with many children not being vaccinated and an increase in deaths.

2.5 Problems with peer reviewed papers

Peer reviewed papers are polished up at the writing stage to make them more persuasive than they are in reality. The rhetoric of a paper is very important, and style of writing does matter, but has been given little attention in the literature. A professional scientific editor can make quite a difference to a paper because it will then come across much better. If the paper is on a current, 'Hot Topic', it will arouse more editorial interest and will probably be more likely to be published. Of course, funding bodies for research are also likely to have a special interest in these, 'Hot Topics', and many of the same persons who are on the funding organisation will later review the papers at the publication stage.

3. Conclusion

The greatest problem in autism research and indeed, psychiatry and clinical psychology generally is heterogeneity. It is impossible to get two samples of subjects completely identical and therefore, there are problems with generalisations to the general population. There was an attempt to establish, 'pure autism', with diagnostic instruments like ADI, but this was never possible to do and was never likely to be accomplished. The concept of, 'pure autism', does not exist. We have to develop more psychiatric and psychological models to deal with research in autism.

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References

- [1] Charman T., Gotham K.: Measurement issues: Screening and diagnostic instruments for autism spectrum disorders – lessons from research and practise. *Child and Adolescent Mental Health*, 2012; 18; 1, <https://doi.org/10.1111/j.1475/3588.2012.00664.x>.
- [2] Robins D., Fein D., Barton M., Green J.A.: The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive Developmental Disorders. *Journal of Autism and Developmental Disorders*, 2001; 31: 131-144.
- [3] Hess P.: Popular screen may mistake intellectual disability for autism. 2020, <https://www.spectrumnews.org/news/popular-screen-may-mistake-intellectual-disability-for-autism/>
- [4] Hackethal W.: A fifteen-month-old baby with delayed communication and social milestone: Can autism be reliably diagnosed? *Neurology Times*, June 5th, 2019. Downloaded 19th October 2019.
- [5] NICE: Autism. London: The British Psychological Society – Royal College of Psychiatrists, 2012.
- [6] Fitzgerald M.: The clinical utility of the ADI-R and ADOS in diagnosing autism. *British Journal of Psychiatry*, 2017; 211: 117.
- [7] Ventola P., Kleinman J., Andy P., Barton M., Allan S., Greene J.: Agreement among four diagnostic instruments for autism spectrum disorders in toddlers. *Journal of Autism and Developmental Disorders*, 2006; 36: 839-847.
- [8] Baird G., Simonoff E., Pickles A., Chandler S., Charman T.: The prevalence of disorders of the autism spectrum disorder in a population cohort of children in South East Thames. *Lancet*, 2006; 368: 210-215.
- [9] Feinstein A.: A history of autism. Wiley-Blackwell, 2010.
- [10] Fitzgerald M., Matthews P., Birbeck G., O'Connor J.: Irish families under stress: Planning for the future of autistic persons: A prevalence and psychosocial study in the Eastern Regional Health Authority. Eastern Health Board, 2000.
- [11] Wing L.: Autistic Disorders Diagnostic Check List, 1987. In Fitzgerald M. et al. Irish families under stress. Planning for the future of autistic persons. A prevalence and psychosocial study in Dublin. Eastern Health Board, 2000.
- [12] Kanner L., Eisenberg L.: Early infantile autism. *American Journal of Orthopsychiatry*, 1943-1955; 26: 55-65.
- [13] Scull A.: Madness in civilisation. Thames & Hudson, 2015.
- [14] McGregor A., Sex matters. London: Quercus, 2020.
- [15] Ioannidis J.: Contradicted and initial stronger effects in highly cited clinical research. *Journal of the American Medical Association*, 2005; 13: 2, 218-228.
- [16] Bottema-Beutel K., Crowley S., Sandbank M., Woynarowski T.: Errors of omission: Why we are deeply concerned about research on autism therapies, 2020. <https://www.spectrumnews.org/opinion/errors-of-omission-why-we-are-deeply-concerned-about-research-on-autism-therapies/>
- [17] Gernsbacher M., Yergeau M.: Empirical failures of the claim that autistic people lack a theory of mind. *Archives of Scientific Psychology*, 2019. <https://doi.org/10.17605/osf.io/3r2qy>.

[18] Fitzgerald M.: Neurodiversity is an attitude of mind to deal with stigma – a re-evaluation of concept. 2020, https://www.researchgate.net/publication/346108762_neurodiversity_an_attitude_of_mind_to_deal_with_stigma_a_re-evaluation_of_concept.

[19] Wakefield A., Murch S., Anthony M., Linnell J., Casson D., Malik M.: Ileal lymphoid nodular hyperplasia, non-specific colitis and pervasive developmental disorder in children. *Lancet*. 1998; 351: 9103: 637-641.