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Review Article

THE NEW DIAGNOSTIC CRITERIA OF AUTISM: IMPLICATIONS FOR RESEARCH AND PRACTICE IN THE MIDDLE EAST AND NORTH AFRICAN REGION

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ABSTRACT

This article discusses history of autism diagnosis and provides an update of the latest diagnostic criteria. This is essential before starting any research or intervention for people with autism anywhere in the world, particularly in the Middle East and North African (MENA) region where autism diagnosis and public perception about this condition is challenging. We start by defining autism and its diagnostic criteria according to American Psychiatric Society (DSM-5 2013), including an outline of some characteristics of people with autism and some related terms e.g. the notion of a 'triad of impairments', 'Autistic Spectrum Disorder' (ASD) and its relationship with 'learning disabilities/difficulties'. We concluded that the latest diagnostic criteria according to DSM-5 2013 is very helpful in terms of treating autism as spectrum of different abilities and allow for designing a bespoke individualised interventional approaches to help them. As far as autism in the MENA region is concerned we argue that the new diagnostic criteria if implemented will result in improving the life of people of autism and their families.

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INTRODUCTION

This article discusses the new diagnostic criteria of autism as outlined in The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5 2013) which was published by the American Psychological Society (American Psychiatric Association, 2013), and its implications for research and practice in the Middle East and North African (MENA) region. A prerequisite for this is an understanding of autism.

History of autism

The literature presents different views about what precisely 'autism' is. The term was used firstly by Bleuler in the beginning of the 19th century to describe children who had retired from joining in the social world (Cumine and Stevenson, 2000). Leo Kanner in 1943 invented the label 'early infantile autism' (Cumine, V. L 2000 *et al*; Cumine, VL 1998 *et al*), to describe children who had "never been participants in the social world" and those who seemed egocentric with severe social, communication, and behavioural problems. Subsequently Hans Asperger in 1944 used the term "autistic" or "autism" to describe children who "found it difficult to fit in socially" (Frith, 1989). It was suggested that Kanner and Asperger were the "pioneers in recognising that autism is a developmental disorder where the behavioural demonstrations change with the age and ability of the person with autism" (Cumine and Stevenson, 2000). In summary, it could be argued that Asperger (1944) described the abler children with autism disorder and Kanner (1943) described the children who had classic or severe autism (Frith

and Hill, 2003), who seemed egocentric with severe social, communication, and behavioural problems.

Definitions of autism

In 1980 autism was included, for the first time, as a separate category 'infantile autism' in the third American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) (Cumine, VL 1998 *et al*; Howlin, P. 1998). This was later changed to 'autistic disorder' in 1987. Then in DSM-IV (American Psychiatric Association, 1994) it was mentioned as 'Autistic Disorder' and sometimes referred to as 'early infantile autism', 'childhood autism', or 'Kanner's autism'.

Since then, the area has attracted many researchers to investigate this mystifying behaviour and to discover more explanations and definitions of autism from their specialist point of view. For example, Howlin (1998) defined autism as a "complex disorder" that influences several features of performance (Howlin, 1998), where Aarons & Gittens (1998) described it as a "cognitive disorder" that influences every feature of social development. (Aarons and Gittens, 1998)

It is clear that autism is a complex disorder with individuals affected potentially showing a wide range of disabilities (Irwin, *et al.* 2011); Matson and Kozlowski, 2011). People with autism are faced with a wide range of difficulties in social interaction, social communications and social imagination, which in turn has great impact on their learning and development (Lecavalier *et al.* 2011).

METHODS

This is essentially a scoping review in which the Pubmed, google scholar and ERIC databases were searched (no language or time restrictions) to find relevant articles on autism in the MENA region and the diagnostic criteria used in these countries. Literature on the new diagnostic criteria according to DSM_V were also searched to build an argument to inform practitioners and parents on the MENA region to use them.

The Current status of Knowledge

Autism in the MENA region

There has been few published research on the prevalence of autism in the developing world in general and in MENA region in particular (Al-Salehi, *et al.* 2009, Al-Farsi, *et al.* 2011), including Libya (Zeglam, and Maouna, 2012). For example, a study on the Sociodemographic factors on Arab children with Autism Spectrum Disorders concluded that, the clinical presentation of ASD may be shaped by cultural factors that are likely to affect the specific diagnosis of autism and inform the subsequent intervention techniques in this region of the world (Amr, *et al.* 2012). Unquestionably, these sociodemographic and cultural factors could be added to the already known challenging circumstances affecting reaching the accurate diagnosis of cases with autism in MENA region. The following challenging points could be attributed to the underreporting of autism in the Arab world:

- Difficulties in the diagnosis arising from the lack of appropriate training of paediatricians who conduct the diagnosis of autism.
- Many Parents are unaware of the autism condition.
- Those parents who are aware of autism might be reluctant to consult specialists about their children either because of fear of stigmatising their children or they are unaware of the need of the early diagnosis and intervention.

There is little awareness in the MENA region about the most updated diagnosis strategy and diagnostic tools. Some experts have adapted DSM-IV for use in this region. In some Arab countries the commonly used tool to diagnose autism was derived from criteria adopted from DSM-IV for the use in India (Amr, *et al.* 2012). However, there is now a new updated version of diagnosis which simplified the diagnosis approach and could be of value in screening for and devising intervention for people with autism.

Diagnostic criteria according to DSM-V

The complexity of the disorder has created challenges for categorisation and diagnosis of children and adults with autism. There are two general approaches to the diagnosis of autism: categorical and dimensional (Volkmar, *et al.* 2012). In the categorical approach, a cut-off point is usually used to assign individuals into a category of the condition, while in the dimensional approach a tool or instrument is used to assess development and monitor progress. Each approach has its own advantages, challenges and usages in practice and research. In general, categorical approaches are considered advantageous for screening purposes while dimensional approaches are typically used to monitor changes (Volkmar, *et al.* 2012). The latest new diagnostic criteria of autism by

DSM-5 in 2013 has adopted the dimensional model and ignored the categorical approach.

Since 1980, there have been more updates to the DSM, and in the most recent version DSM-5 (2013) autism is identified as having the following major criteria (1):

1. Persistent deficits in social communication and social interaction across multiple contexts.
2. Restricted, repetitive patterns of behaviour, interests, or activities.
3. Symptoms must be present in the early developmental period.
4. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
5. These disturbances are not better explained by intellectual disability.

DSM-5 advises that severity is based on social communication impairments and restricted repetitive patterns of behaviour. The severity of autism can be of three levels according to the associated symptoms. Level 3 describing individuals requiring “very substantial support” because of their severe deficits in social communication and obsessed repetitive behaviour that “markedly interfere with functioning in all spheres”. Level 2 individuals require “substantial support” as they have marked deficits in social communications and their repetitive behaviour appears “frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts”. Level 1 has a lesser degree of these symptoms but individuals still require “support”.

The other classification system, which is used to diagnose autism, is the International Classification of Diseases (ICD) which is similar to DSM. In ICD10 (World Health Organization, 1992) which was developed by the World Health Organisation (1993), autism is mentioned under the heading ‘Developmental disorders’ (F80-F89) and sub-heading ‘Pervasive developmental disorders’ (F84) i.e. ‘Childhood autism’ (F84.0), also called ‘Autistic disorder’, ‘Infantile autism’, ‘psychosis’, ‘Kanner syndrome’. ICD-10 lists a range of symptoms in social interaction, communication and repetitive behaviour, and for a child to be diagnosed with autism at least four symptoms of the list have to be evident (WHO in 1993). Both DSM and ICD emphasise that the characteristics have to be diagnosed or noticed by the age of 3 years. However, DSM clearly alerts users of its criteria that “Symptoms must be present in the early developmental period but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life” (DSM-5 2013, p.50).

Autism as a spectrum disorder

A commonly used expression for autism is ‘Autistic Spectrum Disorder’ (ASD) which is defined by the UK’s National Autistic Society (NAS. 2015) as a “complex lifelong developmental disability”. ASD has been, also, referred to as ‘Autistic Spectrum Condition’ (ASC), because it is less stigmatising and it mirrors the “cognitive strength” of people with autism along with their disability (Baron-Cohen, *et al.* 2009). People with ASD can show extensive discrepancy in their symptoms of severity (Anagnostou, *et al.* 2014), and although they share some specific difficulties, their condition will affect them in different ways. The spectrum ranges from

severe to mild where the mild end is known as 'Asperger Syndrome' (AS) or 'High functioning autism' (HFA) (DSM-IV 1994) (American Psychiatric Association, 1994).

It was argued that while the DSM-IV classification "provides a gross distinction between groups of people with mild and severe disabilities" The DSM-5 has collected all the historical diagnoses of autism in one category and asks clinicians to rate severity according to three degrees according to symptoms and the need for support (Ward-Horner, *et al.* 2011). Accordingly, there is no longer 'Pervasive Developmental Disorder' (PDD) as a diagnostic category on its own, neither is there a category named 'Pervasive Developmental Disorder Not Otherwise Specified' (PDD-NOS).

The core characteristics or features of autism are impairments in communication and social behaviour, and restricted and repetitive behaviours. They exist in a range or "spectrum of severity" that could affect the child's interaction with others to varying degrees (Cuvo, 2011). In the new DSM-5 dimensional approach, individuals with low-functioning autism, characterized by low IQ, more frequent and severe symptoms, and less adaptive functioning, are placed at one end and those with HFA who have higher IQ and few and milder symptoms and less disability are seen as being at the other end (Irwin, *et al.* 2011).

Indeed, the concept of autism as a spectrum or a continuum has been around for a long time but it is only now that many clinicians, researchers and practitioners have adopted this model. The autism spectrum approach allows clinicians to account for the variations in symptoms and behaviours from person to person (DSM-5), as well as variations and development over time.

Autism and learning disability/difficulty

Autism often co-exists with other developmental disorders. For example, high levels of anxiety or depression have often been usually reported in individuals with autism (Gillberg, 2011). There is also a high prevalence of other conditions such as 'dyslexia' or 'dyspraxia' with autism (Anagnostou, *et al.* 2014). In individuals with the mild form of autism the occurrence of other mental disorders is less common than in those at the severe end of the spectrum. It was suggested that Asperger or HFA students are not affected by general learning difficulties and are likely to benefit from a general education and may even be particularly talented in some disciplines, whereas students with severe autism might have additional 'learning difficulties' (Jordan, 2001). Not unexpectedly, in case of severe autism, Gillberg (2011, p.22) stated that he would be "surprised to find one single case in which there was no other mental or physical disorder" (Gillberg, 2011).

Epidemiological studies have shown that autism overlaps with the diagnosis of learning disability in 68% of autism cases (Lecavalier *et al.* 2011). Other research suggests that the deficits in executive function, can lead to a misconception by researchers and clinicians alike that the individuals affected have a genuine verbal or non-verbal learning disability, when in fact they might be suffering from a weakness in visual perceptual motor skills which is predominant in ASD (Lovecky, 2005).

Wing (2011) argues that most people become familiar with ASD as a single diagnosis, but complications arise with other diagnoses or labels (disabilities and/or behaviour), where the

affiliation to the autistic spectrum is vague and "indeed confusing" (Wing, 2011). Wing recommends that these labels are considered as part of the autistic spectrum – a view reflected in DSM-5 (2013) which considers autism as a continuum from mild to severe (Wing, 2011).

The Triad of Impairments

The deficit of social proficiencies in people with autism is often referred to as the 'triad of impairments' (Wing, 1996). These impairments are seen as consisting of:

1. a communication impairment: people with autism tend to have difficulty understanding and also using verbal and non-verbal communication,
2. a social (relationship or interaction) impairment: people with autism tend to find it difficult to join and empathise with other people,
3. an impairment of social imagination: people with autism tend to have rigidity in language, thinking and manners and this might explain their problems with imaginative role play or pretend play.

The notion of the triad of impairments was first proposed by Wing & Gould (1979) who concluded that the concept of the triad can describe the social difficulties that characterise children with autism. It has been widely considered as one of autism's specific concerns and is one of the main common views of the nature of autism (Aarons and Gittens, 1998, Wing, 2011).

More recently, National Autistic Society (NAS, 2015) has summarised the triad as difficulty in social interaction, social communication and social imagination which might affect people with autism differently i.e. they may be experiencing "different degrees of difficulty". In the new DSM-5 (2013) the triad of impairment has become a "dyad" or "reduced" (NAS, 2015), where the impairment in social interaction and social communication are now combined in one category i.e. 'Social Communication'.

The triad of impairments is considered by many to be caused by an underlying difficulty with what is often referred to as a 'Theory of Mind' (ToM) deficit (Doherty, 2008). It is stated that the triad of impairments is "underpinned" by ToM, which is considered as one of the important cognitive theories of autism (Howlin, 1998).

Additional characteristics of children and people with autism

In addition to the above-mentioned characteristics, people with autism may present with other characteristics. In 1943, Kanner observed "a good rote memory, an obsessive desire for the preservation of sameness and no real communicative intent" in the children who attended his clinic (Neumärker, 2003). Another group described by Asperger in 1944 had complications in language and difficulty in using and understanding "facial expression or gesture" (Cumine, and Stevenson, 1998). Other characteristics might include absence of or difficulties in using speech, being withdrawn, showing resistance to change (rigidity), sleeping difficulties, repetitive movements (prolonged rocking and spinning), poor eye contact and unpredictable negative behaviour. Such children might also have obsessive interest, hyper-sensitivity (Cumine and Stevenson, 2000) and echolalia; the automatic repetition of vocalisations made by another person (Frith, 1989). Further,

concerning sensory responses Volkmar *et al.* argue that some individuals with ASD might respond extremely to common stimuli such as touch, sound and visual stimuli and they also might have a high rate of seizure disorders. Finally, one of the most worrying and difficult behaviours that people with ASD might face is 'self-injury' or 'self-harm' behaviour, which might indicate an underlying mental health issues such as depression or anxiety (Aarons and Gittens, 1998). In summary, people with autism tend to be lonely, withdrawn and isolated from the social world surrounding them. Incidentally, this matches exactly the meaning of the word 'Autism' in Latin and as translated in many other languages.

CONCLUSION

DSM-5 suggests seeing autism as a continuum spectrum of severity. In DSM-5 the dimensional model was applied to assess development and progress of people with autism which used to monitor any change might occur from time to time. Simultaneously, DSM-5 discounted any categorical approach including Asperger S or High FA. While this might be criticised as it could reduce the stigmatization of the autism categories at the lower spectrum of the disease and this would, undoubtedly, encourage parents and carers of individuals with susceptible symptoms to seek advice and treatment. The new diagnostic approach would also allow for individualised intervention according to the severity of the symptoms. As far as autism in the MENA region is concerned, we argue that the new diagnostic criteria if implemented will result in improving the life of people of autism and their families.

Competing interests

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Authors' contributions

The two authors contributed equally to this review.

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