Research in Developmental Disabilities 31 (2010) 705–712

Contents lists available at ScienceDirect

Research in Developmental Disabilities

The relationship between carers' report of autistic traits and clinical diagnoses of autism spectrum disorders in adults with intellectual disability

Sabyasachi Bhaumik [a], Freya Tyrer [b,*], Mary Barrett [a], Nyunt Tin [a], Catherine W. McGrother [b], Reza Kiani [a]

[a] Leicestershire Learning Disability Service, Leicestershire Partnership NHS Trust, Groby Road, Leicester, UK
[b] Department of Health Sciences, University of Leicester, 22-28 Princess Road West, Leicester LE1 6TP, UK

ARTICLE INFO

Article history:
Received 11 January 2010
Accepted 25 January 2010

Keywords:
Autistic traits
Autism spectrum disorders
Autism
Asperger syndrome
Intellectual disability
Learning disability

ABSTRACT

It is often difficult to determine the triad of impairments and whether autistic features are the consequence of intellectual impairment or autism spectrum disorders in people with intellectual disability (ID). The aim of the current study was to investigate the relationship between carer-reported autistic traits and independent diagnoses of autism spectrum disorders (ASD). Data were collected on carers' subjective report of autistic traits and clinical diagnoses of ASD. Of 1145 adults with ID identified, 220 (19%) individuals had a diagnosis of ASD, and 778 (68%) individuals had at least one autistic trait. Optimal sensitivity and specificity were achieved with two or more autistic traits (sensitivity 63%; specificity 79%) and the positive predictive value increased substantially as the number of autistic traits increased. However, a significant proportion of individuals with ID who did not have a diagnosis of ASD also displayed autistic traits. Our findings suggest that in the absence of other measures, the presence of autistic traits can serve as a useful proxy measure for ASD in research (and/or clinical settings). However, although information on autistic traits may help healthcare practitioners to identify people with possible ASD, it cannot be used alone to make a formal diagnosis.

1. Introduction

Autism spectrum disorders (ASD), including childhood autism and Asperger syndrome are neurodevelopmental disorders, originally reported to occur in between 0.1 and 0.3% of the general population (Bouras, Holt, Day, & Dosen, 1999; Fombonne, 1999; Kielinen, Linna, & Moilanen, 2000). However, recent epidemiological studies on ASD have revealed a higher prevalence of approximately 1% in the general population (Baird et al., 2006; Brugha et al., 2009). Childhood autism and Asperger syndrome were first described in the 1940s (Asperger, 1944; Frith, 1991; Kanner, 1943). Since then, the concept of a broader spectrum of autism disorders has been introduced (Gillberg, Persson, Grufman, & Themner, 1986; Wing & Gould, 1979).

There are no universally accepted criteria for diagnosing ASD, but a triad of impairments in social interaction, communication and imagination have been described (Wing & Gould, 1979). The varying severity of these impairments is then believed to determine the ASD diagnosis. In the United States, most clinicians use DSM-IV criteria (American Psychiatric

* Corresponding author.
E-mail address: fct2@le.ac.uk (F. Tyrer).

0891-4222/$ – see front matter © 2010 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ridd.2010.01.012

Association, 1994) to diagnose ASD, whilst in the United Kingdom and the rest of Europe, the ICD-10 classification system (World Health Organization, 1992) is more commonly used. The two systems have many similarities, particularly in the diagnostic criteria for the 'core' syndrome of childhood autism (ICD-10) ('autistic disorder' in DSM-IV). Both describe qualitative impairments in social interaction and in communication, and restricted, repetitive and/or stereotyped behaviors manifesting in the first 3 years of life. Both systems also require the presence of core deficits in social interaction and restricted/repetitive behavior patterns in the absence of a clinically significant general delay or retardation of language or cognition for a diagnosis of Asperger syndrome. However, there are small differences that might lead to Asperger syndrome being under/over-diagnosed using one system compared with the other (Leekam, Libby, Wing, Gould, & Gillberg, 2000). In addition, ICD-10 has a separate category for atypical autism (F84.1) and other pervasive developmental disorder (PDD) (F84.8), whereas DSM-IV categorize these under "PDD not otherwise specified" (PDD NOS, 299.80).

A substantial proportion of people with ASD also have intellectual disability (ID). Until recently this proportion was believed to be as high as 75% (Gillberg, 1995), but changes in diagnostic criteria and increased awareness of ASD in the general population has led to a marked rise in diagnoses of ASD in people without ID (Wing, 1996; Wing & Potter, 2002). Nonetheless, recent reports on the prevalence of ID in those with ASD (either in children or adults) vary substantially, ranging from as low as 15 to 17% (de Bildt, Systema, Kraijer, & Minderaa, 2005; Gillberg & Soderstrom, 2003) to as high as 42–70% (ADDMNS Year 2000 Principal Investigators, 2007; Bouras et al., 1999; Kielinen et al., 2000; LaMalfa, Lassi, Bertelli, Salvini, & Placidi, 2004). As for the prevalence of ASD in people with ID, this is reported to be between 8 and 20% (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; de Bildt et al., 2005; Wing & Gould, 1979), depending on diagnostic instrument, concept and ID severity.

Although the presence of brain damage and severe and profound ID are not exclusion criteria for a diagnosis of ASD, making an accurate diagnosis of ASD in these client groups can be particularly challenging for several reasons. First, it can be difficult to ascertain whether the presence of autistic features is the consequence of brain damage/ID or ASD. Some autistic features, such as impairments in communication and difficulties in socialization might be indicative of a low IQ rather than ASD. Secondly, in those with severe and profound ID, communication and imagination may not be present to any significant degree due to the person's developmental level, although social interest is normally present soon after birth. Thirdly, those people with severe to profound ID and significant physical co-morbidities may have very limited behavioral repertoires with which they can express themselves, which can make assessment difficult. Profound congenital deafblindness, which may be present in this population, makes the presentation even more complicated. Pre-lingual and profound sensory deficits are reported to (either independently or through accompanying brain damage) adversely affect acquisition of Theory of Mind and abstract thinking which might result in autism/autistic like symptomatology (Hoevenaars-van den Boom, Antonissen, Knoors, & Vervloed, 2009; Pring, 2005).

Finally, diagnoses of ASD rely on the identification of impairments affecting social interaction, communication, and imagination, and for people with limited intellectual ability it may not be possible to determine these without personal knowledge of the individual presenting for treatment. For these reasons, practitioners often rely on carers' accounts because they are possibly the only reliable way of establishing illness.

The present authors have identified a combination of five carer-reported autistic traits to act as a proxy measure for diagnosing ASD in the absence of other indicators (Bhaumik, Branford, McGrother, & Thorp, 1997). The five traits were chosen from the Disability Assessment Schedule (DAS) (Holmes, Shah, & Wing, 1982) and consist of impairments in speech, social skills and empathy and presence of elaborate routines and marked or constant stereotypies (Box 1). Previous research suggests that these traits occur in approximately half of adults who use specialist ID services (Bhaumik et al., 1997). However, the precise relationship between carers' report of autistic traits and clinical diagnoses of ASD remains unclear.

Box 1. Autistic traits on the Leicestershire Learning Disability Register.[a]

Minimal speech
Unable to ask for things s/he wants or talk about things s/he has done

Poor quality of social interaction
Does not interact—mainly aloof, indifferent or bizarre
Interacts to obtain needs only—otherwise indifferent
'Unwarm'—does make social approaches, but these are peculiar, naïve or even bizarre. The person does not modify behavior in light of these responses, needs or interests of those whom s/he approaches. The interaction is one-sided and dominated by the person being rated

Lack of empathy
No or limited empathy

Simple stereotypies
Marked repetitive activities (e.g. rocking, flicking figures, etc.), especially when unoccupied, although may be controlled by close supervision or being kept fully occupied—often a constant feature, present each day

Elaborate routines/obsessional behavior
Has elaborate routines of the kind and intensity found in early childhood autism

[a] From the Disability Assessment Schedule (Holmes et al., 1982).