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What is available for case identification in autism research in mainland China?

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ABSTRACT

Little is known about research on Autism Spectrum Conditions (ASC) in mainland China. The few available studies in mainland China have shown the screening and diagnostic instruments for ASC used in mainland China were different from the West. Literature on screening and diagnostic instruments and criteria were reviewed and current available instruments were identified and evaluated. Eight screening instruments and two diagnostic instruments were identified. The Clancy Autism Behaviour Scale (CABS), the Autism Behaviour Checklist (ABC) and the Childhood Autism Rating Scale (CARS) were the most frequently used instruments in mainland China. They were adopted from the West more than two decades ago for detecting individuals with Childhood Autism but not the whole autism spectrum. Standardised instruments need to be validated and adopted into autism research in mainland China.

1. Introduction

The term Autism Spectrum Conditions (ASC) is used to describe a group of childhood-onset neurodevelopmental disorders characterised by impairments in social interaction and communication, and the presence of repetitive and stereotyped behaviours, interests and activities (World Health Organisation, 1993). Recent epidemiological studies reported that the prevalence estimate of ASC was around 1 percent of the general population, which is much higher than earlier studies indicated (Fombonne, 2009). As the prevalence estimates increase, the detection of ASC has drawn more attention worldwide than before (Baird et al., 2001; Barbaro & Dissanayake, 2010; Rice et al., 2007).

Recent epidemiological research has adopted a two-stage process for case identification in the general population (Baron-Cohen et al., 2009; Kim et al., 2011). The first stage is screening and the second stage is diagnostic assessment. The aim of screening is to identify and distinguish individuals who are more likely to have the condition of interest from those who are less likely to have it (Webb, 2005). Screening instruments are used to detect the condition before the usual time of diagnosis. In terms of ASC, the screening instruments are usually checklists with questions related to possible autistic features. Individuals with positive screening results are then referred for more standard diagnosis (Porta, 2008). Screening for autism has been proposed by many researchers (Baird et al., 2001; Duby & Johnson, 2009). Different

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screening instruments have been developed to detect potential cases in specific age ranges and/or for specific subtypes on the spectrum (Norris & Lecavalier, 2010; Vostanis, Smith, Chung, & Corbett, 1994).

In terms of diagnostic assessment, as there has been no absolute test for ASC, because no clear biomarkers are available, diagnostic instruments for ASC largely depend on the information from parents and direct observation of the affected child. A number of diagnostic instruments have been developed, such as the Autism Diagnostic Observational Schedule (Lord, Rutter, DiLavore, & Risi, 2001), the Diagnostic Interview for Social and Communication Disorder (Wing, Leekam, Libby, Gould, & Larcombe, 2002), the Autism Diagnostic Interview Revised (Rutter, LeCouteur, & Lord, 2003) and the developmental, dimensional and diagnostic interview (Skuse et al., 2004). The combination of the ADOS and the ADI-R has been used more frequently in recent large-scale epidemiological research for case confirmation of ASC (Levy, Mandell, & Schultz, 2009).

There has been limited research on the current situation of ASC in mainland China, which refers to 23 provinces and 5 autonomous regions, excluding Hong Kong and Macao. A previous review reported that the prevalence of Childhood Autism in mainland China was 10.3 per 10,000, which was much lower than Western estimates (Sun & Allison, 2009). In most previous Chinese studies, the Clancy Autism Behaviours Scale (CABS) and the Autism Behaviour Checklist (ABC) were used as screening instruments, and the Childhood Autism Rating Scale (CARS) was used as diagnostic instrument. These instruments are not frequently used in prevalence studies in the West, which suggested that the screening and diagnostic instruments used in mainland China are different from those used in Western studies (Sun & Allison, 2009). This paper sets out to investigate the utility of instruments for ASC that have been applied to the Chinese population in mainland China. Learning from what is available can help to decide whether it is necessary to introduce and adopt more recent and advanced instruments for autism research to mainland China.

This paper has three objectives: to identify the instruments and criteria that have been used for case identification for ASC in mainland China; to report the validity and reliability of these instruments; to summarise the current methodology and propose directions for future research in ASC in mainland China.

2. Methods

2.1. Literature searches

Systematic literature searches were conducted using four databases from the establishment year of each database to 2011 for publications related to screening and diagnostic instruments for ASC in mainland China (Figs. 1 and 2). The two English databases were PubMed and Web of Knowledge. The other two were Chinese databases, including China Web of Knowledge and Weipu. The search methodology used in the English and Chinese databases was not identical. In the English databases systematic searching was conducted using three steps: Step 1 used the terminology of conditions such as 'autism'

PubMed (searched on 27th December 2011)
Years (1966-2011)
Step 1: "Autism"/all subheadings [MeSH] OR "Autistic Disorder"/all subheadings [MeSH] or "Autism Spectrum"/all subheadings [all fields] OR "Pervasive developmental disorder"/all subheadings [MeSH] OR "Asperger"/all subheadings [all fields]
Step 2: "China"/all subheadings [all fields] OR "mainland China"/all subheadings [all fields] AND results from Step 1
Step 3: "Validation"/all subheadings [MeSH] OR "Screen"/all subheadings [MeSH] OR "Screening test"/all subheadings [MeSH] OR "Mass screening"/all headings [MeSH] AND results in Step 2

Web of Knowledge (searched on 27th December 2011)
Year (1950-2011)
Step 1: "autism"/ [Topic] OR "autistic disorder"/ [Topic] OR "autism spectrum"/ [Topic] OR "pervasive developmental disorder"/ [Topic] OR "asperger syndrome"/ [Topic]
Step 2: "China"/all subheadings [all fields] OR "mainland China"/all subheadings [all fields] AND results from Step 1
Step 3: "validation"/ [Topic] OR "screen"/ [Topic] OR "screening test"/ [Topic] OR "mass screening"/ [Topic] AND results in Step 2

MeSH (Medical Subjects Headings) The National Library of Medicine controlled vocabulary for indexing articles in PubMed.

Fig. 1. Search strategy for identifying validation studies in English databases.