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About some difficulties in the epidemiological studies of autism

Abstract

Pervasive developmental disorders are developmental pathologies with a prevalence of one in four hundred. Standardised diagnostic observation is possible thanks to measurement tools such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revisited. Here we shall examine difficulties encountered during our experience with 22 families in Laos in March 2015. Problems were observed with the translation of family interviews and psychopathological terms, the adaptation of material for children during ADOS consultations, as well as the points evaluating visual and emotional social interaction. Resolving these problems is partially linked to the social-economical development of the country.

Keywords: Pervasive Developmental Disorders. Cultural Adaptation. Lower-Income Countries.

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Introduction

Pervasive developmental disorders are developmental pathologies with a prevalence of one in 400.[1] With the help of standardised assessment scales they are detected and diagnosed by observing behaviours and social interaction. The current study is based on these disorders' descriptions in the International Classification of Diseases (ICD), tenth edition.[2] Diagnostic axes are: qualitative alteration of reciprocal social interaction, qualitative alteration of communication, and the restrictive, restrained and stereotyped nature of behaviours.

Diagnostically-oriented observation is standardised thanks to examination tools such as the Autism Diagnostic Observation Schedule (ADOS)[3] and the Autism Diagnostic Interview-Revisited (ADI-R).[4] The second edition of the ADOS was published in 2012. The ADOS is composed of four modules designed for different ages and developmental stages. Each of these four modules contains exercises that allow the examiner to observe and spot important findings in social interaction, play and stereotyped behaviour. These observations can yield a diagnosis, although they must be complemented by results of the ADI-R and an intelligence test. The ADI-R is a semi-directive interview composed of 86 questions. It takes into consideration the age of at which first symptoms first appeared and the family environment. The intelligence test can be conducted using a verbal or non-verbal scale, depending on the child's capacities. We will not be studying the validation or the intercultural validity of these tests, although these are important issues. In order for these testing tools to be valid for the populations they evaluate, they must first undergo a validation study, with which a diagnosis can be affirmed to be valid. We are going to examine adaptation of the ADOS only, although difficulties were also encountered with the ADI-R. Such difficulties must be taken up in further articles.

Here we will attempt to discuss difficulties we encountered in our experience in Laos in March 2015, during which we conducted 22 diagnostic consultations (data is currently being published). The objectives of this article are threefold: to supply information related to official translations of diagnostic tools throughout the world, to underline important difficulties encountered in adapting the ADOS to clinical experience in Laos, and finally to highlight problems related to epidemiological data collection, specifically in developing countries.

Translating diagnostic tools in the world

The ADI-R is an observation chart based on what parents or other educators observe. It helps establish a history of the child's difficulties, using interviewees' memories and their everyday experience with the child. Some facts are useful simply for background information, while others, such as the appearance of first signs or of early-age (18 months) regression in functioning level, may greatly influence the professional in his or her diagnostic hypothesis. The ADOS is a doctor or psychologist's direct observation of the child with the aid of play material, tools and toys that are familiar to the child. These two observation tools represent the "Gold

Standard", meaning they are considered the international reference in establishing the validity of a fact, in this case the presence of an autistic disorder. Their validation requires a translation supervised by a scientific committee. Translations are currently available in 18 languages for the ADI-R and 22 languages for the ADOS. These translations do not signify clinical validation.

Conducting the ADI-R brings to light difficulties specific to translation. Our team provided for use of a translator for family interviews. In addition to the translator's presence possibly influencing parents' responses, technical complications were also apparent. Prior work with the translator was therefore necessary to decide on terms to use for diagnosis, with important matters such as the difference between general developmental delay and developmental disorders not being apparent in the Lao language at first sight and not being understood by families. Links must be established between vocabularies of families, the translator and the professional. This difficulty must be seen in connection with the country's level of development: the general level of education and sensitivity to disability is closely linked. It can thus be said that families from rural areas with little access to information have greater difficulties understanding the terms of the ADI-R as they are used for diagnosis and explaining a child's difficulties. Work on local cultural representations of concepts used in the evaluation process is therefore necessary in order to make these concepts more accessible.

Cultural adaptation of screening tools

The diagnosis of autism is done via observation by doctors and psychologists and their judgements on the child's use of the different objects he or she is presented with. From our personal experience in Laos, we were able to define three major axes upon which to work towards adapting the ADOS. Slight modifications can take place on any one observation point without being truly significative. We replaced, for example, the toy on wheels, which is usually a dog or a cow in the original test, with a locally-made coconut turtle, which is more likely to be encountered in the child's everyday reality. We believe, nevertheless, the following axes to be of fundamental importance.

First axis: Free play, interactive play, demonstration tasks, pretend play with use of a doll

The first point is an observation of the child's free play. Several toys are placed at the child's disposal in the room when he enters, without any specific instructions being given. The child is free to use the toys entirely, partially or not at all. The first aim is to see whether the child is interacting and how. The second aim is linked to knowledge of the objects, since the child is expected to use the toys in a symbolic or functional manner. That said, a child may be unable to use these objects, not because of a cognitive deficit, but due to surprise, fear or ignorance of the object's function. A lack of interest can therefore be misinterpreted. Children from rural areas do not have access to the type of toys mentioned in the ADOS. Reactions of pronounced fear or indifference may be observed without being able to know if it is a symptom. At least three children left the examination room in a clear state of distress at the sight of the doll. In interviews with parents, games of pretend play were understood to be the use of real and functional tools to mimic an action on an object that is also real. For the ADOS, the pretend play game is about the child's ability to complete a fictional action, and is often done with a miniature reproduction of an object (for example a dollhouse tea set), or even without an object at all (such as using one's hand as a telephone). A redefinition of the concept at the time of interview may end up being necessary to obtain desired information.

The assessment point involving holding a birthday party turned out to be completely undoable in the vast majority of cases. For this assessment, a birthday cake and candles are built out of modelling clay with the aim of organising a party for the doll. We encountered two major obstacles. The first was the children's ignorance of the material (doll and clay). The second was ignorance of the ritual (blowing out birthday candles), which is typically Western. Only children with access to television could understand this ritual.

Second axis: Evaluation of eye contact and person-to-person facial expressions

This assessment category evaluates the quality of reciprocal social interactions, which is the first diagnostic axis for autistic disorders. It covers evaluation of visual contact, including the duration of visual contact, quality of facial expressions directed toward others with the aim of expressing emotion, as well as use of visual contact during social interaction.

These behaviours and their observations are strongly influenced by cultural habits of gaze, means of nonverbal communication and emotional expression, as Sebastian Miellet *et al.*'s[5] work has shown with regard to cultural aspects of emotional expression and understanding. In European countries, avoiding eye contact is one of the primary signs of autistic disorders, noticed by parents and seen as a major red flag in a young child's assessment. Among the general population avoiding eye contact is seen as a sign of uneasiness or social difficulties, both for children and adults. In other cultures, and especially those of Asian countries, avoiding eye contact carries a positive social meaning. The normal-pathological divide for this trait may then be different for an observer from an Asian culture. Such a difference can impact data for milder autistic disorders. Its study would potentially shed light on neurological mechanisms linked to the autistic person's gaze and how it is influenced by the person's environment. In clinical activity, we encountered difficulties in classifying this trait, since differences in eye contact between autistic and non-autistic children was insignificant.

Third axis: Specific or idiosyncratic use of tonality

This category explores language-related pathological aspects, particularly intonations in language prosody. Lao, like many Asian languages, is a tonal language. One of the assessment points examines language anomalies, including those related to tonality of speech. However, with this assessment point having been standardised in relation to non-tonal languages, its observation cannot be adapted to a tonal language. Furthermore, a linguistic study is necessary for every translation and adaptation of the ADOS in order to

understand the normal order in which linguistic phonemes are learned in children's development.

We have observed, in both Laos (from personal observation and parental feedback) and Thailand (from the Autism Research Centre's report), a preference for English-language expression among children with autistic disorders who don't possess functional language-use in their mother tongue. These observations need to be further developed, with the absence of tonality in English potentially being the cause of this linguistic behaviour. A recent study suggests there being difficulties understanding differences in intonation on the part of individuals with autistic disorders.[6] This behavioural trait could offer diagnostic clues for children whose native language is tonal if further studies confirm these results.

Problems in collecting epidemiological data on autism

Means of data acquisition are quite homogenous across the world.[7] Over the course of time and in different regions of the world, diagnostic scales and criteria have undergone slight modifications. Today still, as we have seen, not all countries have the same tools of observation at their disposal. Therefore, "several factors can at least partially explain the increase in prevalence of ASDs (autistic spectrum disorders), such as modified diagnostic criteria in successive versions of the DSM (Diagnostic and Statistical Classification of Mental Disorders) and ICD, diagnostic substitution and buildup and the variability of evaluation procedures in different studies".[8] This variability does not allow us to completely affirm the identical character of the pathological entities that have been studied, also calling into question the value of diagnoses given, as well as their therapeutic implications. In a search for precision, it would be equally important to study the intercultural variability of signs of autism all over the world with the help of a fixed and repetitive procedure.

Data from developing nations is lacking. We must continue our efforts in translating and validating standardised scales, as well as conducting diagnostic studies in these countries and comparing observations made by several teams with diverse cultural backgrounds. Through this study we hope to find further answers as to the rise in the prevalence of autism in recent years, as well as the importance of sociocultural factors in how autistic disorders are expressed and observed. For a child to be assessed, a parent or educator must first express concern. This concern is based on the ideas these adults hold with regard to mental health and disability. At what moment will they esteem that the child has a disorder that requires medical attention? Medical consultation is a luxury for certain families lacking access to health services, which can be common in particular regions.

During our project in Laos, most families (61%) interviewed were alarmed by an absence of speech, and 17% by unusual behaviour. Juneja *et al.*[9] speak of similar observations in India. Less spectacular signs of developmental problems, such as lack of pointing or avoiding social relationships may very well go unnoticed in developing regions of the world, impacting epidemiological statistics. It is probable that, as in Western nations,[8] greater public knowledge of autistic disorders in the coming decades will be correlated with an increase in their prevalence.

Conclusion

We must consider obstacles to evaluating the prevalence of developmental disorders, both in order to improve families' access to care, as well as for scientific epidemiological needs. During our project we were able to underline difficulties regarding translation, which involve the lexical field used by Western professionals, the translator's proper training as to appropriate terms for complex psychopathological concepts, as well as limitations caused by the population's level of education and sensitivity to disability. The second problem to be resolved involves the concrete adaptation of ADOS assessment points, which must be accomplished by a multicultural team with wide knowledge of developmental disorders. Finally, we must consider children's language specificities, which requires observing apparition of phonemes and use of tones in normal development for children speaking tonal languages. Use of English and absence of tonal recognition among children with autistic disorders whose native languages are tonal may give valuable information as to these individuals' cognitive functioning.

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