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Adaptation of assessment of pervasive developmental disorder in lower income countries

Leslie Marneau

Clinical Psychologist, A Bus for Autism, France.
*Corresponding author: lesliemarneau@hotmail.fr

Abstract

The project aimed to investigate the possibility of adaptation of assessments for diagnosing Pervasive Developmental Disorder in a Southeast Asian country. This paper presents a personal project, at first created for humanitarian purposes. The main difficulties were the nonadaptation of the material, and the confusion between autism and mental retardation. The project took place in a special education centre in Vientiane, Laos. It involved 23 children who first screened positive with M-CHAT. Out of the 23 children participating in the project, 13 were diagnosed with a PDD. The scores at ADOS and ADI-R matched, showing that the use of the gold standard may be considered as relevant in Laos. However, a study on a bigger sample has to confirm this conclusion. The results showed the need to adapt the material of ADOS, as well as the necessity of collaboration with local experts and developing awareness of autism. This study result is inconclusive concerning the epidemiology of autism in Laos, regarding the small size of the sample. The factors associated with the difficulties of the diagnosis process in Laos may be found in others area of South-East Asia. The specificities of Laos concerning the diagnosis of autism are: tonal language, lower access to information, lower or no access to specific medical resources on autism, rural population, difference in the use of toys, reasons of parental first worries, diversity of population and languages.

Keywords : Laos, autism, adaptation, lower-income, epidemiology

Introduction

This study presents a report of a project in Laos, attempting to diagnose Pervasive Developmental Disorders in children coming from Vientiane and its countryside. We decided to base the current study on the disorders' descriptions in the International Classification of Diseases, tenth edition (WHO, 2013). The ICD-10 describes three axes of troubles: qualitative alteration of reciprocal social interaction, qualitative alteration of communication, and the restrictive, restrained and stereotyped nature of behaviours.

The exact aetiology of PDD is still unknown, though research heads toward providing evidence for genetical origins, associated with others factors (Chaste & Leboyer, 2012). The diagnosis of PDD is made by observing and scaling typical behaviours as described in the ICD-10. This observation must be effected by trained professionals, with the help of standardized scales.

Most studies on PDD are made in richer countries, though most infants are born in poor countries (Tomlinson & Swartz, 2003). This is one of the reasons why we question the adaptability of the assessments in non-western countries.

Per those studies, the estimated global prevalence of autism spectrum disorders is 62/10,000 (Elsabbagh, Divan, Koh, Kim, Kauchali, Marcín & Yasamy, 2012). However, the data in

lower-income countries is limited and the research of scientific literature in medical databases was unsuccessful in finding official epidemiological data in any of those countries. Several hypotheses can be made to explain this difference, namely, the lack of local experts, the difficulty replicating protocols, translating assessments, and accessing appropriate diagnosis centres. The World Health Organization recommends the use of the international recognized Gold Standard (Tang, Guo, Rice, Wang & Cubells, 2010) to diagnose PDD. It consists of the combination of the Autism Diagnostic Observation Schedule - 2 (Rutter, DiLavore, Risi, Gotham & Bishop 2012) and the Autism Diagnostic Interview – Revisited (Rutter, Le Couteur & Lord, 2003) added to an intellectual efficiency evaluation. The ADOS is a standardized schedule, based on observation. It has to be administrated by a trained psychologist or physician. The observation of autism is prone to subjectivity, per social and medical norms. Also, autistic children can show different symptoms according to the context e.g. the absence of the use of tones in tonal languages, observed in Laos, Thailand and China. Administration of the ADOS requires specific material, including toys. Those toys were originally chosen according to the criteria of regular children's games in western countries. They aim to enlighten the presence, or absence, of certain abilities, as symbolic play or imitation (frequently lacking in PDD). Most of the children met during our project came from rural Laos, and were not in contact with such toys at any stage of their lives. The observation, related to the reaction of the child in front of the toys, can be biased by normal surprise or fear (Marneau, 2016). Particularly, the materials included a doll, which was ignored or rejected by most of the children, regardless of the presence of significant sign of autism.

The ADI-R is a semi-structured interview with parents or care givers. It has to be administrated by a trained clinician. The interview lasts one to two hours, and required a translation in the case of our project. There is no official Lao or Thai translation of this assessment. The presence of a translator is necessary during the entire time of the interview, as well as during the restitution interview to communicate the results of the evaluation to the parents. The presence of a translator can result in biased answers by the parents.

Objectives

The aim of the project was to start estimating the possibility of the use of the gold standard and its validity in Laos. To lead further research on the prevalence of PDD, this project is considered as a start in low-income countries of Southeast Asia. The global prevalence cannot be concluded according to our study. According to the current development of services for children with autism, other research, translations, and developments will be necessary to better understand the epidemiological data.

Methods

Study design

Instruments

Diagnostics were made according to the ICD-10 criteria: presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interest (WHO, 1989).

The ADOS was made by a clinical psychologist trained in autism. The assessment was administrated in a room reserved for this use. In order to provide adapted material for the items of the ADOS, we used the material of the Thai Development Skills Inventory for Children from birth to 5 years of age, standardized test for assessing child development in Thailand (Sirithongthaworn, Narkpongphun, Pongtaweeboon, Itsarapong, Kasemsuk, Pila, ... et al., 2013).

The ADI-R was made by a French paediatrician trained on its use. A consultation room was

provided. A French-Lao translator was present during the interview with the parents. We used the official French translation of the ADOS and ADI-R. The Denver Developmental Screening Test (Hansen, 2013) was used during the medical consultation, before the administration of the ADI-R. The group assessment was made with the Behavior Summarized Evaluation Revisited (Barthélémy, Roux, & Adrien, 1997). The BSE-R is a scale developed in order to follow-up the evolution of autistic symptoms during the psycho-educative treatment. It presents a check-list of autistic behaviours, with a 1 to 4 scale. The choice of this scale was made for its simplicity of use during a group observation. The group observation was made in a playground room, and during lunch. As table manners differ from one country to another, it seemed important to us to also observe children during this time.

To assess intellectual efficiency, the Social and Cognitive Evaluation Battery (Adrien, 2008) was administrated. The SCEB is an assessment of young infants designed for children with autism or developmental disorder. The aim of the evaluation is replacing the classical intelligence scale, when the behaviour or development of the patient doesn't allow its use. It has been recently used in several countries.

This paper focuses on the use and adaptation of the international gold standard for diagnosis of autism: ADOS and ADI-R.

Site of study

Laos is a country with 6.77 million inhabitants and a very diverse population. The main language is Lao, a tonal language from the Tai group, and can be divided into 5 sub-groups. All have tones. About 210,000 inhabitants live in the capital, Vientiane. Most of Laos' population live in rural areas, with few having access to medical services. There were no medical personnel trained to diagnose autism, to aid our investigations during our study, as well as today. Consequently, important data is missing.

The study was set in a school providing special education for children with autism or other developmental disorders. To attend the school, children need to be evaluated and diagnosed with PDD. Children attending the school before the study were diagnosed abroad, but many children with disabilities are not attending school, mainly because of the lack of special schools and educators.

Selection of participants

The actual study started in March, however the selection of participants was made three months earlier. Parents were contacted by the general secretary of the school, or were informed of the study by an announcement. This selection limits the diversity of the participants, and is a consequence of the lack of access to information.

A first screening was administered by a teacher, with the Modified Checklist for Autism in Toddlers (Robins, Casagrande, Barton, Chen, Dumont-Mathieu & Fein, 2013) in a translated Thai language non-official version. The children with positive scores in the M-CHAT were selected: 23 children participated in the entire assessment including 87% of boys. When asked, most parents answered that autism is the absence of language, which was the first cause of consultation.

The participants stayed 4 days at the centre, in order to be observed in group and individual consultations. Some parents also stayed during the day.

Results

PDD was diagnosed for 13 children, including 2 girls (15%), representing less than 1 girl for 6 boys. The average age of first worry was 29,95 months (2,5 years), the reason of first worry was the absence of language in 14 cases (60.8%), followed by behavioural issues (26%).

The average age was 5 years and 6 months, the minimum was 2 years and the maximum was 10 years. The number of cases of children with positive scores in M-CHAT was 23. Among this sample, only 15 children showed specific behaviour and were assessed with the ADI-R: the results show 8 negative scores, and 7 positive scores. The 8 non-assessed children were diagnosed with other disorders or none (table 2).

The positive scores represent 30.4% of the children who screened positive in the M-CHAT. The efficiency of the M-CHAT was not significant compared to the ADI-R results.

Table 1: Age, sex and parents reason relevant to parental 1st worry Legend : L = language ; B = Behaviour ; D = Development ; S = Social Interaction; M = male; F = female

Age of exam (years, months)	Sex M	Sex F	Age of first worry in months (Months)	Reason of first worry
5	/	-	18	L
3	/	-	13	S
5	/	-	32	L
3	/	-	12	L
4	/	-	27	L
7	-	/	48	B
4	/	-	-	L
6	/	-	-	L
6	/	-	30	L
10	/	-	-	D
9	/	-	24	-
7	/	-	36	B
4,6	/	-	30	B
5,6	-	/	36	L
5	/	-	14	B
5	/	-	15	L
7	/	-	36	B
2	/	-	18	L
6	/	-	30	B
3,6	/	-	18	L
7	/	-	-	L
3,6	-	/	16	L
3.6	/	-	18	L

Table 2: Results of assessments

Age of exam	5	3	5	3	4	7	4	6	6	10	9	7	4,5	5,5	5	5	7	2	6	3,5	7	3,5	**3,5**
Gender	M	M	M	M	M	M	M	M	M	M	M	F	M	F	M	M	M	M	M	M	M	F	**M**
ADOS																							
Module	1	1	1	1	1	4	1	-	2	-	1	1	1	1	1	-	1	1	-	1	1	1	-
Communication	8	9	0	6	2	2	0	-	1	-	7	1	5	3	7	-	7	3	-	3	0	6	-
Interaction	14	10	11	5	2	3	6	-	4	-	11	1	11	8	12	-	14	3	-	5	0	8	-
Play	3	3	1	3	3	0	1	-	1	-	4	3	4	2	3	-	4	4	-	2	2	4	-
Behaviour	6	3	5	2	0	2	0	-	0	-	4	3	4	3	5	-	4	0	-	1	0	4	-
ADI																							
Interaction	23	18	23	18	3	2	19	-	0	-	28	11	17	21	20	-	24	-	-	21	-	14	-
Communication	11	14	8	5	10	2	9	-	0	-	10	6	8	12	13	-	9	-	-	8	-	7	-
Behaviour	5	5	5	2	1	2	0	-	0	-	2	1	4	8	5	-	3	-	-	2	-	2	-
Signs -36 m.	4	4	2	0	5	0	5	-	0	-	4	4	4	4	5	-	1	-	-	5	-	4	-
BECS								-															
Cognitive	1,43	0,57	2,57	1,86	-	-	3,14	-	1,29	-	-	2,00	3,00	2,00	2,71	3,86	-	1,29	1,00	2,86	-	2,86	-
Emotional	0,33	0,33	2,00	0,89	-	-	2,22	-	2,78	-	-	3,00	3,89	1,89	1,89	2,89	-	1,33	0,89	1,89	-	1,22	-
Global	0,81	0,56	2,25	1,44	-	-	2,63	-	2,31	-	-	2,75	3,75	2,19	2,44	3,56	-	1,50	1,00	2,44	-	2,06	-
ABS																							
Overall Total	38	23	26	21	14	6	1	2	11	-	0	11	20	19	29	2	32	0	6	21	2	27	
Total grey	24	17	14	14	5	4	0	2	5	-	0	5	10	7	20	1	20	0	6	12	2	18	
Total 11, 13, 16	3	1	1	3	1	0	0	0	3	-	0	2	3	5	1	0	4	0	0	4	0	4	

Diagnosis	PDD	PDD	PDD	PDD	ID	none	ID	lang.	ID	other	PDD	PDD	PDD	PDD	PDD	Dysph	PDD	Delay	ID	PDD	none	PDD	Lang.
Comorbidity	ID							-		-	ID	ID		ID			ID						

Administration of the ADOS was judged relevant for 17 of the 23 children: the results show 11 positive scores for PDD, representing 47,8% of the children who previously screened positive. The efficiency of the M-CHAT was not significant compare to the ADOS results. Out of the 23 children, 6 were assessed with neither the ADOS nor the ADI-R, due to an absence of clinically significant symptoms of autism. However, the lack of language gave them positive scores in the M-CHAT (26%). Out of the 23 children, 13 (56%) were diagnosed with Pervasive Developmental Disorder including 5 (38.4%) children presenting an important mental retardation. Among the entire sample, 4 children were diagnosed with mental retardation without significant autistic features (17.3%), and 3 children with a severe language disorder, non-related to autism (13%). 1 child was deaf, without clinical sign of other pathology.

The ADOS and ADI-R concluded the same diagnosis in 14 cases out of 15. The BSE-R concluded the presence of autistic disorders in 13 cases. Those 13 cases were all positive at ADOS and ADI-R. The results of the ADOS, ADI-R and BSE-R matched.

Discussions

Material adaptation

The project aimed to investigate the possibility of use of the gold standard to diagnose autism in Laos, and its needs of adaptation. The most significant issue of adaptation concerned the doll used to evaluate the ability of the child to play symbolic games. Indeed, children from rural Laos are not used to playing with plastic dolls. We had to stop the administration of the ADOS twice, as the child was scared of the doll. Other children were totally uninterested in the doll; we couldn't be certain however if it was for pathological reasons. The birthday party (ADOS item) was not doable, due to an important and significant difference of culture. The party, as done in the ADOS, doesn't exist in rural Laos. The item consists of creating a play-dough cake for the doll, singing and blowing out the candles. The doll, the play-dough and the birthday cake are not a part of daily life of those children. It was difficult to evaluate if the surprise and understanding was due to pathological reasons. A deeper analysis of the ADOS material and its possibilities of adaptation, will be necessary in a future study. Collaboration with local researchers would be necessary to adapt the material. We couldn't obtain the WNV (Wechsler & Naglieri 2006), therefore we used the SCEB. However, the WNV would have been more relevant.

Cultural adaptation

We noticed that both the concepts of language and communication are confused by the global population, concerning the symptoms of autism. Additionally, the absence of language is considered as a pathognomonic sign of autism. This could explain the high rate of false positive in the M-CHAT (43.4%). An important difficulty of translation occurred during the diagnosis process. At first, we had to train the translator about autism, in order for her to be able to explain the situation to parents. However, she had difficulties finding the right Lao term. The difference between mental retardation and developmental disorder was not understandable in the Lao language. We had to use a paraphrased English term to provide accurate information to parents. In our sample, 54% of children with PDD also presented a middle to severe intellectual disability. However, there are several reasons why the found rate of comorbidity could not reflect the reality: the use of an inadequate tool, a non-representative sample, an inadequate screening, a lack of awareness about other symptoms of autism, particularly those concerning communication issues that are not directly linked to absence of language e.g. eye

contact, loneliness, misuse of objects. Children presenting functional language may not be considered as autistic despite the presence of those symptoms.

Limits

Our project presented numerical, geographical and methodological limits. Indeed, concerning the sample, too few children were involved. All the families came from Vientiane and its surrounding areas. The team should be mobile to access all types of the population, regardless of the social situation. We think that the sample of children doesn't reflect the reality of the global children population. A large part of the population is living in country areas with little access to information and special education. In this context, most children with disabilities stay at home and the families may not have access to information about the project. The selection of the children has to include a larger part of the population.

We trained the translator in autism vocabulary. However, a part of the information can get lost in translation. The diagnosis based on ADI-R can suffer from this lack of accuracy. A local clinician trained in autism would be necessary in this situation.

All of our team were European. The methodology of the study must include double-blind observation with local experts to discuss observation bias caused by the cultural appurtenance of the clinicians, as well as improving the adaptation of the item materials.

A detailed socio-demographic study should be done to indicate the factors determining the reason of first worries of parents, as it could have an influence on the age of diagnosis (Soe & Linn, 2016), and could indicate the priority of awareness program.

A bigger sample of children with a specific methodology is needed to obtain relevant epidemiological data for this area.

Implications

The factors associated with the difficulties in the diagnosis process in Laos may be found in others area of South-East Asia. The specificities of Laos, concerning the diagnosis of autism are: tonal language, lower access to information, lower to no access to specific medical resources on autism, rural population, difference in the use of toys, reasons of parental first worries, diversity of population and languages.

The use of the M-CHAT may not be adapted, in regard of the false positives rate obtained in our study.

Conclusions

To conclude, this first project showed a high need of collaboration with local clinicians in order to increase the possibilities of futures studies and to adapt the material of the ADOS. The project should involve more participants in several areas of South-East Asia. The very low awareness of autism and its signs, limits our possibilities to diversify the sample of participants, and probably increases false positive at preliminary screening. The worries of the family seem to be focused on the development of language abilities, which reduces the presence of young and high functioning children. The less possibility of special education can also increase the score of mental retardation, the learning difficulties linked to autism not being compensated.

In order to increase knowledge on autism and its treatment, links and partnership between international researchers have to be developed. In the case of significant difference in the rate or the signs of autism in different areas, the result could lead to information on aetiology. The scores at ADOS and ADI-R (as well as BSE-R) matched, showing that the use of the gold standard may be considered as relevant in Laos. However, a study on a bigger sample has to confirm this conclusion.

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