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REVIEW ARTICLE

Psychiatric pathology evaluation using the ChA-PAS (version for children and adolescents of the PAS-ADD) among children and young people with severe and profound intellectual disability

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Abstract: Mental disability referred to here as Intellectual Developmental Disorder (IDD), according to the ICD-11 working group, shows a high prevalence of associated psychiatric morbidity that is poorly diagnosed. The dual diagnosis perspective in IDD seeks to clarify this situation in the overall framework of the difficulties presented by individuals with IDD. This article presents the data from use of a tool designed to detect psychiatric pathology in children and young people with IDD, the ChA-PAS (Child Adolescent Psychiatric Assessment Schedules), and evaluates the consistency of the results of the ChA-pAS with psychiatric diagnoses previously reached clinically.
In the results, the vast majority of the study population (91%) presents psychiatric illness associated with IDD, with a predominance of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). The prevailing condition in individuals with profound IDD is ASD, while in individuals with severe IDD, ADHD is most common. The degree of agreement with prior clinical diagnoses was 100%, which supports the hypothesis that ChA-PAS is a useful tool in assessment of this population.
We conclude that even with suitable tools, assessment of individuals with IDD, especially severe and profound IDD, is always a challenge. Using new tools and translating, calibrating and validating them for the Portuguese population could be of benefit to people with IDD.

Keywords: intellectual disability; dual diagnosis; assessment instruments.

Introduction

Intellectual Developmental Disorder (IDD), in the designation used by the ICD-11 working group for mental retardation (ICD-10), is an entity that runs across all areas of intervention in rehabilitation. This reality has always been a source of severe limitations in support for these individuals, because of the difficulty of joining up all the areas that should be covered by the intervention plan.
In particular, in the area of psychiatry and mental health, there is no culture of assessing the specificity and the difficulties of the approach to these situations. Thus there is no specific training on the subject within the curriculum for specialist registrars in psychiatry and mental health, either of adults or children and adolescents, perpetuating a support model that rarely meets the needs of individuals with IDD, their families or the professionals who look after them in rehabilitation institutions, which are usually connected to the social welfare.
Taking these specificities into account, the dual diagnosis approach [1] stands out. This seeks to clarify, within the overall picture of the difficulties presented by individuals with IDD, what is the result of the IDD and what is associated with psychiatric diagnoses which, as mentioned above, are often not recognized but rather included in the picture of IDD.
We believe it is important to produce scientific evidence that alerts the psychiatric community to the reality of dual diagnosis, both as a way of improving the psychiatrist's intervention in these situations and as a means of raising awareness among those responsible for medical training of the need to include this area in the curricula of the specialties.
The higher prevalence of mental illness among individuals with IDD is widely acknowledged. Unfortunately, there are few tools designed for use in this population, and

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those that do exist usually have significant limitations in terms of the populations covered (age, degree of disability), the possibilities for gathering information, and the number of diagnoses they permit.

Objective

This article presents data from use of a tool designed to detect psychiatric pathology in children and young people with IDD, the ChA-PAS (Child Adolescent Psychiatric Assessment Schedules), and assesses the consistency of results from this tool with psychiatric diagnoses previously reached clinically.

The data presented correspond to part of the psychiatric evaluation from a more extensive study in progress at the *Centro de Recuperação de Menores D. Manuel Trindade Salgueiro* (CRM), of the *Irmãs Hospitaleiras do Sagrado Coração de Jesus* (IHSCJ), the Multidimensional Study of the Children and Adolescents of the CRM with Severe and Profound ID. The main objective of this study, among others, is to create a multidisciplinary assessment kit that meets the needs of the various technical areas of intervention with children and young people with severe and profound IDD. Data from the overall study will also be published at a future stage.

CRM provides care for 120 female residents between the ages of 3 and 17 years. It is a necessary condition that they have a diagnosis of Intellectual Development Disorder. The CRM currently prioritizes situations of dual diagnosis (IDD and other disorders in the context of mental health and psychiatry) and multiple disabilities (IDD and other sensory, expressive or motor disabilities) as the most specific clinical area of intervention of its practice. Its geographical scope of intervention is nationwide.

Its specificity lies in the characteristics of the technical staff: unlike the usual situation in institutions connected with rehabilitation, this includes medical and nursing staff. It consists of a psychiatrist. a general practitioner, a pediatrician, a dentist, 14 nurses, a psychologist, a social worker, an occupational therapist, a psychomotor therapist, a physiotherapist, a speech therapist, two social educators, 52 carers, four with specific responsibility for supervising occupational activities, two special education teachers and six sisters from the congregation of the IHSCJ who direct and coordinate services as well as providing care.

The ChA-PAS belongs to a set of four tools referred to collectively as PAS-ADD (Psychiatric Assessment Schedules for Adults With Developmental Disabilities) (http://www.pas-add.com/), designed to improve detection and diagnosis of mental health problems in individuals with IDD. The PAS-ADD Clinical Interview is a semi-structured clinical interview developed from the PAS-ADD 10 initial version. It is intended for use by trained professionals, typically psychiatrists or psychologists, and permits precise diagnoses within the main diagnoses of ICD-10 and DSM-IV-TR. The PAS-ADD Checklist is a questionnaire of 25 items, written in plain language, designed to be used primarily by careers and family members. These are the people who are the first to notice any change in the behavior of those for whom they care, so as to decide on the need for an assessment in a clinical setting. The Mini PAS-ADD is a semi-structured questionnaire designed to detect psychiatric symptoms, conducted by a team member, who while they do not have to have training in psychiatry or psychology, must nevertheless receive the appropriate training to use the questionnaire. It is intended for the most direct carers or to family members of the person with IDD. Lastly, the ChA-PAS is the most recent element of the PAS-ADD family, and is the result of countless requests from professionals because of the minimum age limit for use of the Mini PAS-ADD. It too is intended for use by team members who have received the appropriate training; either the child or young person with IDD can be interviewed, or a carer or family member, or both.

With the exception of the PAS-ADD Checklist, none of these tools is designed to determine a diagnosis, but they permit a more precise understanding of the need for clinical assessment to define the presence of any disorder. They have the great advantage of allowing personnel with no training in psychiatry or psychology to detect a possible psychiatric disorder, greatly extending the scope for assessment of the population with IDD, in different contexts and at all ages and degrees of disability.

The ChA-PAS is a questionnaire with 97 items, organized into seven sections, associated with psychiatric symptoms, quantified on a severity scale of 2 or 4 points. The items are based on ICD-10 (WHO, 1992). Some items refer to core symptoms of specific pathologies, while others are common to various pathologies. Thus the ChA-PAS generates a score on eight symptom scales: psychosis, manic episode, depressive episode, anxiety disorder, obsessive-compulsive disorder, conduct disorder, attention deficit hyperactivity disorder (ADHD), and autism spectrum disorder (ASD). Each scale presents a reference score to identify the likely presence of the corresponding mental health problem.

Epidemiology

According to various studies [2] quoted by Albuquerque (2000) [3] IDD has a prevalence, of approximately 1%, when at least two evaluation criteria are used, intelligence quotient (IQ) and an adaptive behavior scale. This figure differs significantly from what we find if we use only IQ, namely 3%. This also explains the variation in results between the various studies. The prevalence of severe and profound IDD is much lower than that of mild and moderate IDD (0.4% versus 2.5 to 3%), and its causes are usually better defined [4] .

Studies of prevalence of mental illness in IDD are much scarcer. Nevertheless, all existing studies agree on the idea that individuals with IDD have increased vulnerability to mental health problems [5-7] . There is a prevalence of 30 to 40% of mental illness in individuals with IDD, which corresponds to approximately four times the prevalence in the general population. This ratio is maintained regardless of the specific pathology we consider. Thus, for schizophrenic disorders the prevalence is 3% [8] , while anxiety disorders occur in approximately 40% of people with IDD (Raghavan, 1997) [9] . Mood disorders are the exception, with prevalences lower than or similar to the general population in the few studies conducted between 1.3 and 3.7% for depression [10] , 6.6% for all mood disorders [5] .

Method

The sample corresponds to the total universe of CRM residents between 3 and 25 years of age with severe and profound IDD.

The ChA-PAS is developed in the context of the multidimensional study in progress at CRM, as already mentioned, and relates to the detection of psychiatric pathology. Use of this tool involves a principal informant, who may interview the person to whom the scale applies or other persons who have regular contact with that person (family, other carers), and a second informant, who accompanies the selected person in other contexts (usually the teacher, at school).

Because there are no versions translated and validated for the Portuguese population, we have decided to use the original version, taking care that it is always the same informant using the scale. We believe that either a free translation on our part or use of other versions already translated (Spanish, French) could affect results more significantly.

Thus we have chosen the CRM psychiatrist as first informant for each person selected, as this is the team member most directly connected to psychiatric pathology. This made it possible to use the scale without any specific training being required. In addition, the institution's psychiatrist knows all the persons selected and has access to all other carers. As second informant, the reference professional for the person selected was asked to take responsibility for that role, because he or she has privileged knowledge of the person and regularly collects information from other informants.

All data-gathering options were used, from interviewing the selected person, according to the feasibility of their participation, to participation of other carers connected to basic subsistence activities, other technical interventions and the pedagogical area. All data available from throughout the selected person's history were considered, as many of the changes considered are not present at the time of the interview. Moreover, reference to the period covered by data gathering is something that has to be stated at the start when completing the ChA-PAS.

Characterization of the selected person was based on the data in their individual clinical files (biographical data and previous diagnoses). The study included the entire population at the CRM with severe and profound ID within the defined age range.

Results

Sample

A total of 33 female residents of the CRM with ages between 3 and 25 years were assessed. Of these, 23 had severe IDD and 10 profound IDD.

From the prior data in the clinical file of each resident assessed, it was found that 30 (90.9%) of them had a psychiatric diagnosis, 28 (84.8%) had a somatic pathology, 31 had two or more associated pathologies (93.9%), mainly epilepsy, seen in 10 (33.3%), and, lastly, none of the residents assessed had no associated pathology.

Table 1: Characterization of sample according to data from clinical file

Intellectual Development Disorder	Severe (N=23)	Profound (N=10)	Total (N=33)
Gender	Female	Female	
Age 3 < 6		1	1
Age 6 < 12	2	3	5
Age 12 < 25	19	8	27
Psychiatric disorder	20	9	29
Somatic disorder	16	13	29
Psychiatric and somatic disorder	16	9	25
No other diagnoses	0	0	0

Administration of the CHA-PAS

After administering the ChA-PAS instrument, we observed a predominance of ratings above the reference score for diagnoses of autism spectrum disorder (ASD) (n=13, or 43.3%), and attention deficit hyperactivity disorder (ADHD) (n=11, or 36.6%), which is in agreement with the experience of professionals who work in this area and the data in the literature.

Several cases show ratings below the threshold of significance (defined by the scale in the score form) for conduct disorder, but all have a significant rating for ADHD, a diagnosis that includes the changes in conduct identified. Others present ratings below the threshold for psychosis and obsessive disorder, but all belong also to cases that score significantly for ASD, which includes the psychotic and obsessive symptoms identified.

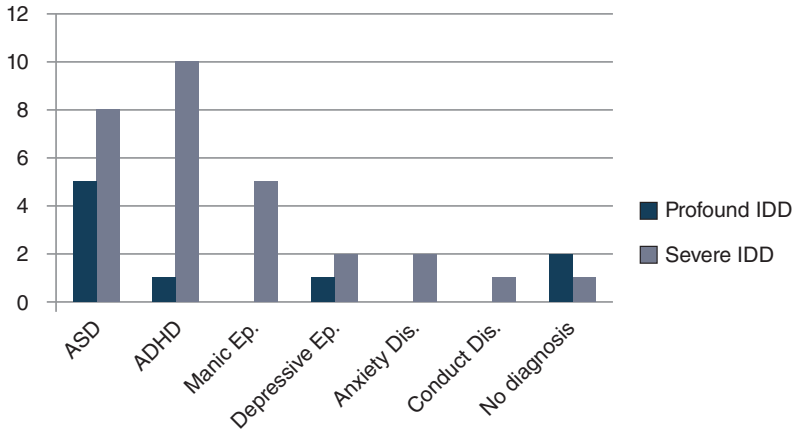
Lastly, although only two individuals score for anxiety disorder (AD), there are a further 11 who, although they score

significantly for AD, score also for ADHD and ASD. These are more specific diagnoses that include non-specific anxiety changes present in many pathologies and that cannot therefore be scored as an isolated diagnosis in these cases.

Table 2: Results of administration of the ChA-PAS

Intellectual Developmental Disorder (n:33)	Severe	Profound	Total	Notes
ASD	8 (26.6%)	5 (16.6%)	13 (43.3%)	
ADHD	10 (33.3%)	1 (3.3%)	11 (36.6%)	
Manic episode	5 (16.6%)	0	5 (16.6%)	
Depressive episode	2 (6.6%)	1 (3.3%)	3 (9.9%)	
Anxiety disorder	2 (6.6%)	0	1 (3.3%)	A further 11 (36.6%) score, included under ASD and ADHD
Conduct disorder	1 (3.3%)	0	1 (3.3%)	
No psychiatric diagnosis	1 (3.3%)	2 (6.6%)	3 (9.9%)	

Chart 1: Results of administration of the ChA-PAS



Discussion and Conclusions

This paper seeks to show the importance of the ChA-PAS instrument in detecting probable psychiatric pathology in children and young people with severe and profound IDD. While the gathering of information was blind in relation to previous diagnoses, the degree of agreement with previous clinical diagnoses was 100%, which supports the hypothesis that ChA-PAS is a useful tool in assessing this population.

Some of the patients studied display a complex, non-specific pathology, in which the syndromic picture includes symptoms common to several pathologies associated with behavioral changes. The ChA-PAS made it possible to identify the diagnosis that best fitted the set of symptoms presented, with significant implications for orientation of the patient's therapy.

The work conducted also enabled us to identify some of the limitations on assessment of this population.

Thus the difficulty of assessing symptoms of a cognitive nature (e.g. suicidal ideation, self-confidence, delusions) was evident, due to the cognitive problems of the individuals assessed. Limits on personal expression also restrict the individual's participation in the study, whether it be the absence of verbal expression, the fact of being bed-ridden, or even not having any possibility of expression (because even facial expression is compromised or stereotyped).

Along with expressive and conceptual difficulties, sensory difficulties, including bilateral amaurosis and total deafness, significantly compromise effective communication with assessors.

Some items namely sleep and appetite are conditional by the institution's routines and medication. Thus, it is fundamental to have recourse to the data in the history of the person assessed to try to understand what their natural functioning is.

Lastly, the fact that the first informant is the psychiatrist who follows the individuals assessed should be taken into account as a significant factor in the results, even if the psychiatrist did not have the previous diagnoses of the persons assessed at hand at the time of the assessment.

Even so, and bearing in mind the limitations mentioned, we may conclude that the vast majority of the study population (91%) presents psychiatric pathology in association with

IDD, with a predominance of ASD and ADHD. The prevailing pathology in persons with profound IDD is ASD, while in persons with severe IDD, ADHD is most common.

The prevalence of psychiatric pathology associated with IDD is much higher in the study population than in the data in the literature (91% versus 30 to 40%). This may be explained by the institutional context in which the study took place. As we have said above, CRM gives preference to individuals with a dual diagnosis, in which IDD is associated with another psychiatric diagnosis, and therefore has a population in which this situation is much more common.

The fact that there is a lesser variety of psychiatric diagnoses in the population with profound IDD is in agreement with the data in the literature. However, we cannot but question it in view of the limitations referred to, in particular as regards the expressive capacities of the persons observed, all the more so since this fact is of most relevance in persons with multiple disabilities, in whom those limitations are most evident.

Future orientations

Even with suitable tools, assessment of individuals with IDD, especially severe and profound IDD, is always a challenge. Therefore, more studies are necessary using this or another instrument designed to detect probable psychiatric pathology in individuals with IDD, to confirm the data from this study, in order that more professionals may gain experience and confidence in use of these tools, and to extend the evidence of this reality.

Using new tools and translating, calibrating and validating them for the Portuguese population could be of inestimable value to individuals with IDD, by helping all those who work with them to identify the presence of concomitant psychiatric pathology, regardless of the primary training they have received.

Raising awareness of and training health professionals in the situation of dual diagnosis in IDD is paramount, given the scale of this phenomenon. Today there is no structured training in IDD in the vocational journey of the medical class in Portugal at either pre- or postgraduate level. Only by producing scientific evidence of this reality will we have arguments to support curriculum changes that address this subject area also.

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Conflicts of Interest

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