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Development and Initial Utility of the Autism Clinical Interview for Adults: A New Adult Autism Diagnostic Measure

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Abstract

Background: Clinicians use diagnostic interviews to help them gather and organize information collected in the assessment of autism. Most instruments are developed for children and few measures have been developed that are reliable, valid, and appropriate for use in adulthood. This is a significant barrier to providing a high-quality, timely service for adults. The aim of this development study was to assess the initial utility of the recently developed Autism Clinical Interview for Adults (ACIA) for use in autism diagnostic clinical services before further large-scale testing and evaluation.

Methods: We invited adults who had received an autism spectrum diagnosis through a U.K. National Health Service (NHS) multidisciplinary adult autism assessment to participate. Seventeen autistic adults (8 women and 9 men, mean age of 37 years) and four relatives agreed to an interview. The semistructured ACIA interview comprises subject and informant versions, and a self-report preinterview questionnaire. In combination, the ACIA components cover topics relevant to autism and co-occurring condition assessment. We evaluated clinical utility and content validity via comparison with the Diagnostic and Statistical Manual Fifth Edition (DSM-5) and NHS diagnostic reports.

Results: Each interview took between 60 and 90 minutes to complete. Comparison with DSM-5 and the NHS autism diagnostic report demonstrated that the ACIA accurately identified information on core autism characteristics needed for a diagnosis, and identified co-occurring conditions. In response to participant suggestions we revised the interview.

Conclusions: These initial findings support the potential utility and validity of the ACIA for adult autism diagnostic clinical services. Further investigations of the acceptability, utility, and validity of this interview are planned.

Keywords: adult, autism, ASD, diagnosis, Diagnostic and Statistical Manual Fifth Edition (DSM-5), interview

Lay Summary

Why was this study done?

Clinicians use diagnostic interviews during assessments to help gather and record information both from a person suspected to be on the autism spectrum and from an informant (someone who knows them well). However, most autism diagnostic interviews were originally developed for assessing autism in childhood, and few have been developed for use with adults. The lack of diagnostic interviews developed specifically for use with adults makes it difficult to provide a good-quality, consistent assessment.

What was the purpose of this study?

The study tested a new semistructured diagnostic interview called the Autism Clinical Interview for Adults (ACIA). The ACIA includes a questionnaire for people to complete before their interview. This is followed by

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an interview that can be conducted with the person themselves and a separate version to be used with someone who knows them well (if permitted). The interview covers autism traits, strengths and difficulties, and co-occurring physical and mental health conditions. We wanted to find out if the interview is useful for autism diagnostic services by comparing information collected using the ACIA with clinical diagnostic reports.

What did the researchers do?

We invited people who had received a diagnosis of autism from a U.K. National Health Service (NHS) assessment to take part in an interview. We asked them if we could also interview someone who knew them well, and if we could compare their NHS autism diagnostic report with information gathered using the ACIA.

What were the results of the study?

Seventeen autistic adults (average age 37 years; 8 women and 9 men) and 4 relatives/supporters (2 parents, a spouse, and a cohabiting partner) agreed to be interviewed. Each interview took 60 to 90 minutes to complete. A comparison with clinical reports showed the ACIA identified autism traits relevant for a diagnosis, as well as co-occurring conditions (e.g., depression). Participants suggested some ways to improve the interview, and revisions were made.

What do these findings add to what is already known?

There are few diagnostic interviews designed specifically for use with adults seeking a diagnosis of autism. The findings from this study show that the ACIA is a promising new interview.

What are the potential weaknesses of the study?

The study is small. However, it is important to run an initial test study before involving more people and resources in larger studies. Building on these results, we aim to undertake further studies on the acceptability and usefulness of the new interview with a larger number of people, including people from a range of backgrounds.

How will these findings help autistic people now or in the future?

The ACIA has potential for use in adult autism clinical assessment services and as a resource for research and training. The semistructured format helps gather important and relevant information, and the interview length supports feasibility in clinical and research settings. The ACIA has the potential to streamline autism assessments and speed up the process for adults who currently wait a long time for their diagnosis.

Introduction

THERE ARE FEW RELIABLE TOOLS to aid clinicians in the diagnosis of autism in adults, representing a gap in resources.[1–3] Existing diagnostic measures have limitations when used in the presence of co-occurring conditions, which are common in adults suspected of being on the autism spectrum.[4–6] Assessment may also need to proceed without information from a developmental history, which many diagnostic tools rely upon.[7–9] Diagnostic tools also need to be structured and sufficiently detailed to be accurate and efficient for use in specialist and nonspecialist assessment settings and brief enough given service and resource constraints.[8,10–13]

The Family History Interview (FHI) was designed to quantify the broader autism phenotype (traits related to the autism spectrum).[14,15] The FHI characterizes social communication and repetitive behaviors to calculate a standardized score of subthreshold, autism spectrum traits. The FHI was found to be a reliable measure of the broader autism phenotype.[14,15] Building on research experience of using the FHI with adults with a wide range of strengths and impairments, we adapted the FHI to create a new autism diagnostic interview.[14–16] This report describes the development work and findings from a small study assessing utility of the Autism Clinical Interview for Adults (ACIA) for adult autism diagnostic services before undertaking further testing.

Methods

Interview development

We adapted the FHI to create the ACIA during multiple investigator meetings.[17] The investigators included an autistic adult, adult autism diagnostic service clinicians, and clinical researchers. Interview content and format were iteratively refined and modified informed by Diagnostic and Statistical Manual Fifth Edition (DSM-5) criteria.[18]

The ACIA has subject and informant versions and three components. Clients complete the preinterview questionnaire (PIQ) before their face-to-face interview to provide information about demographic characteristics, relationships, living arrangements, and medical history. This information facilitates clients and clinicians preparing for the assessment and informs the diagnostic process about the wider context, including physical and mental health, as well as social and family situation. The semistructured main interview (MI) has

mandatory prompts guiding a systematic approach, and optional prompts allowing further clinical enquiry.[19] The MI covers autism characteristics (22-core items) used to calculate social communication and interaction (SCI) and restricted and repetitive behavior (RRB) scores corresponding to DSM-5 domains.[18] In addition, there are questions covering wider topics, including activities, occupation, and aspirations. Finally, a co-occurring conditions interview (6 items on genetic, neurodevelopmental, and physical health conditions and 10 items on mental health) covers conditions associated with autism and a framework to collect information before any additional diagnoses. Information gathered is coded at item-level as ''0'' (no difficulties), ''1'' (difficulties), or ''2'' (frequent difficulties/impact), and allows assessment of characteristics from child and adulthood.

Piloting

Study inclusion criteria were adults (age 18 years or older) who had received an autism spectrum diagnosis via a U.K. National Health Service (NHS) multidisciplinary team assessment and a relative. The NHS service provided study information to potential participants who had received an autism spectrum diagnosis within the last 5 years. Interested participants contacted the research team. Following consent, an ACIA-trained researcher arranged face-to-face interviews with participants, at a location of their choice. Participants consented to the NHS service providing the research team with a copy of their autism diagnostic report. The researcher was aware of inclusion criteria, but remained blind to diagnostic report content until after all interviews were conducted. The interviewer scored information gathered using the ACIA and mapped onto a coding frame the 22 autism and 16 co-occurring condition items. A second research team member also blind to diagnostic report content independently scored and coded 13 subject interviews (76%), which we used to calculate inter-rater agreement. We then compared information on the coding frames with information in the NHS reports. The interviewer asked all participants about any comments on the interview and recorded responses. We used descriptive statistics to analyze the interview data, and used content analysis to code and group participant comments.[20]

Wales-5 Research Ethics Committee gave the study a favorable opinion (reference: 17/WA/0188).

Results

Seventeen adults who had received a diagnosis of autism spectrum disorder completed the subject ACIA. Four participants' relatives completed the informant version.

Participants took 10–20 minutes to complete the PIQ and none requested help. Table 1 shows information gathered using the PIQ. Each subject and informant MI took 60–90 minutes to complete. Inter-rater agreement on coding for the 22 autism items was 95% and 98% for the 16 co-occurring conditions. There was some disagreement on items relating to the circumscribed nature and intensity of interests.

Because we have not yet developed an ACIA algorithm, we calculated total SCI and RRB scores using the 22 MI core autism items (Table 2a). We then arranged the 22 items into preliminary groups corresponding to DSM-5 subdomains. We totaled participant scores for MI items in each group, and calculated mean scores. DSM-5 criteria for a diagnosis of autism require difficulty present across 3 SCI and ≥ 2 RRB subdomains.[18] Comparing the MI item group mean total scores with the DSM-5 subdomains indicated that the MI

Table 1. Information on Participant Characteristics Gathered Using the Preinterview Questionnaire, Main Interview, and Co-Occurring Conditions Interview

Participant characteristics (n = *17*)			
Preinterview questionnaire		Co-occurring conditions interview	
Female	8 (47%)	Self-reported genetic, neurodevelopmental, and physical health conditions	
Male	9	Chronic physical health conditions	12 (71%)
Age (years)		Attention-deficit/hyperactivity disorder	2 (12%)
Mean (SD)	37 (12)	Motor co-ordination problems	8 (47%)
Range	20–66	Eating problems	3 (18%)
Main interview (subject)		Epilepsy	1 (6%)
		Sleep problems	12 (71%)
Education and highest qualification		Self-reported mental health conditions	
Reported school literacy difficulties	8 (47%)	Anxiety	12 (71%)
Educated to school leaving qualifications	7 (41%)	Depression	11 (65%)
Further education or vocational qualifications	6 (35%)	Bipolar disorder	2 (12%)
Educated to degree or postgraduate level	4 (24%)	Affective disorder summary code	14 (82%)
Employment		Obsessive/compulsive disorder	2 (12%)
Employed	16 (94%)	Substance use disorder	4 (24%)
Professional or skilled occupation	9 (53%)	Personality disorder	1 (6%)
Unemployed long term	1 (6%)	Behaviors that challenge	4 (24%)
		Eating disorder	0 (0%)
NHS report assessment method		Other psychiatric conditions	1 (6%)
Bespoke MDT interview with two clinicians	17		
ADOS[21]	4/17	Intellectual disability[a]	1 (male)

[a]Information from the NHS report.
ADOS, Autism Diagnostic Observation Schedule; MDT, multidisciplinary team; NHS, National Health Service; SD, standard deviation.

Table 2. ACIA Main Interview Total Scores and Comparison with DSM-5 Criteria for a Diagnosis of Autism

(a) ACIA MI total scores

Social communication and interaction (14 items)			*Restricted and repetitive behaviors (8 items)*		
	Subject mean (SD) (n = 17)	*Informant mean (SD) (n = 4)*		*Subject mean (SD) (n = 17)*	*Informant mean (SD) (n = 4)*
Adulthood	17.35 (3.8)	15 (4.7)	Adulthood	4.58 (1.8)	4.25 (2.6)
Childhood	14.17 (4.6)	16.5 (4.9)[a]	Childhood	2.6 (1.4)	2.5 (0.7)[a]
Adult SCI subject mean score for women = 17; men = 18			Adult subject mean RRB score for women = 4; men = 5		
Adult SCI subject mean scores for >37 years of age = 18; ≤37 years of age = 16			Adult subject mean RRB score for >37 years of age = 5; ≤37 years of age = 4		

(b) How participant ACIA MI scores related to their DSM-5 criteria for a diagnosis of autism

DSM-5 subdomains and preliminary corresponding ACIA MI items

Social communication and interaction			*Restricted and repetitive behaviors*		
DSM-5 subdomain[18]	*ACIA MI items (adulthood)*	*Subject mean (SD)*[b]	*DSM-5 subdomain*[18]	*ACIA MI items (adulthood)*	*Subject mean (SD)*[b]
A1: Social/emotional reciprocity deficits	1. Pragmatics 2. Lack of interest in social chat/conversation 3. Reciprocal quality of chat/conversation 4. Social responsiveness 5. Emotional cues and responsiveness	6.8 (1.6)	B1: stereotyped movements or speech	1. Echolalia, idiosyncratic phrases formal and stereotyped speech 2. Ritualized patterns of verbal behavior, repetitive speech 3. Stereotyped or repetitive motor patterns	1.1 (0.7)
			B2: insistence on sameness	4. Rigidity/insistence on sameness 5. Repetitive patterns of behavior, rituals, and routines	1.3 (0.7)
A2: deficits in nonverbal communication	6. Nonverbal communication summary 7. Literal understanding 8. Demonstrativeness 9. Affection	5.7 (1.3)	B3: highly restricted interests	6. Perfectionism	0.9 (0.5)
A3: deficits in developing, maintaining, and understanding relationships	10. Aloof 11. Social shared play and imagination 12. Reciprocal, quality friendships 13. Reciprocal and intimate relationships 14. Social behavior	3.6 (1.1)	B4: hyper/hyporeactivity to sensory input	7. Sensory experiences (positive or negative) 8. Low sensory reactivity	1.2 (0.7)

[a]No childhood total score for two participants whose informant was spouse or cohabitee.
[b]Mean total scores for participants across the preliminary MI item groups; MI individual item scoring: 0 = no difficulties; 1 = difficulties; 2 = frequent difficulties/impact.
ACIA, Autism Clinical Interview for Adults; DSM-5, Diagnostic and Statistical Manual Fifth Edition; MI, main interview; SCI, social communication and interaction; RRB, restricted and repetitive behavior.

did gather sufficient information to identify difficulties corresponding to 3 SCI and ≥ 2 RRB DSM-5 subdomains (Table 2b).

Methods of assessment used in the NHS diagnostic reports are shown in Table 1. Comparison of information from the subject MI 22 autism items with that derived from the NHS diagnostic report demonstrated strong agreement (95%). Differences in recording were noted for social behavior, social play in childhood, intimacy/relationships, and repetitive speech. Agreement on co-occurring conditions was 97%. Overall, the focus of the NHS diagnostic reports was on the diagnosis of autism and compared with the ACIA there was more detail on early development. In contrast, the ACIA systematically collected more detailed information on sensory sensitivities, interests/activities, and co-occurring conditions.

For 13 participants it was not possible to obtain an informant interview. Reasons given by these participants included age and geographical distance to possible informants, limited relationship with family members, and informants' commitments.

Six themes arose from content analysis of subject and informant comments about the ACIA. These included difficulties in availability of informants ($n=5$), item-wording changes ($n=3$), preference for a less structured interview ($n=1$), extra PIQ response options ($n=3$), less repetition in the PIQ ($n=4$), and format changes ($n=2$) (e.g., adding a timetable to structure daily activity questions and developing an informant PIQ). We subsequently made revisions, including removing the term ''pet-phrase'' and shortening the PIQ to reduce repetition.

Discussion

This small development study was an initial evaluation of utility of the ACIA before undertaking further large-scale testing. The findings show that the ACIA allows an interviewer to gather detail on autism characteristics and co-occurring conditions relevant for a diagnostic assessment in an efficient amount of time. ACIA agreement with DSM-5 and NHS reports was good supporting content validity. The findings suggest that the ACIA is a potentially useful resource for diagnostic teams to aid the assessment process and support further investigation of the psychometric properties of the interview.

A strength of the ACIA in contrast to existing diagnostic tools includes the breadth of information collected on autism characteristics and co-occurring conditions through informant and self-report versions. There were similar scores between men and women, however, since we only included those with a diagnosis, further research is needed to investigate whether the ACIA accurately identifies individuals with a range of demographic characteristics and co-occurring conditions, including intellectual disability. Future qualitative evaluation of acceptability with a diverse group of stakeholders is also important.

All participants had already received a clinical diagnosis of autism, so it was not possible to evaluate ACIA performance in people without a diagnosis, or complete psychometric analyses, including assessment of sensitivity, specificity, or severity thresholds. A limitation was that we could only contact someone to complete the informant interview for a minority of participants. Our findings suggest that the self-report ACIA gathers detail covering symptom domains required for a DSM-5 diagnosis of autism for participants when no informant was available. The ACIA may therefore be less reliant on developmental history compared with existing tools—an advantage for some assessments.[7,9] The informant ACIA is another way of supporting clients who may be unable to participate in an interview, including some with an intellectual disability.[22] Autism and intellectual disability commonly co-occur, however, only one participant with an intellectual disability completed the subject ACIA, limiting our findings in this area.[23–25] In future studies, improving recruitment of informants will facilitate investigating psychometric properties of both informant and subject versions and comparing information gathered from each.

The ACIA is a contribution to the currently small number of diagnostic tools available for adults.[1–3] The semistructured format can serve as an important guide for diagnostic accuracy in specialist settings, as well as in mainstream services where skills in autism assessment may be limited, and where case recognition, autism diagnosis, and identification of co-occurring conditions may be particularly difficult.[8,11,13] The study findings are an important first step in evaluating a new semistructured interview that may well be useful for clinical assessment services for adults suspected of being on the autism spectrum, clinician training, and research.

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Authorship Confirmation Statement

J.R.P., B.I., T.B., and A.L. conceptualized the ACIA. All authors contributed to the development of the ACIA. S.W., J.R.P., and Ann Le Couteur wrote the article. J.R.P., B.I., Ian Ensum, Tom Berney, and Ann Le Couteur contributed perspective on the clinical context. B.I. facilitated recruitment. S.W. collected, analyzed, and interpreted the data. Ann Le Couteur assisted with interpretation of data. Ian Ensum reviewed, commented, and provided feedback on draft articles. B.I. and Tom Berney reviewed, edited, and provided feedback on the article. All coauthors have reviewed and approved of the article before submission. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

Author Disclosure Statement

No competing financial interests exist.

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