

Development and Validation of the Autistic Depression Assessment Tool – Adult (ADAT-A) in Autistic Adults.

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Abstract

Background

Depression can be hard to accurately identify in autistic adults due to overlapping characteristics of autism and depression, and depression tools developed for the general population not including unique signs of depression experienced by autistic people.

Methods

Three focus groups and 15 cognitive interviews with autistic adults identified response difficulties and missing autism specific items in a widely used depression assessment tool developed for the general population (PHQ-9). Feedback informed new items in the Autistic Depression Assessment Tool (ADAT-A). A further 9 cognitive interviews and two large online surveys with autistic adults refined the ADAT-A items. Subsequently, 236 autistic adults (87 male, 113 female, 33 non-binary, 18-61 years) completed the ADAT-A online, alongside self-report measures of camouflaging autistic traits (CAT-Q), Intolerance of Uncertainty (IUS-12), Suicidality (SBQ-ASC), Defeat and Entrapment (DES). Analyses explored structural validity, internal consistency, convergent and divergent validity of the ADAT-A in a community sample of autistic adults.

Results

Exploratory factor analysis of the ADAT-A showed evidence in support of a three-factor solution, capturing cognitive-affective and somatic depression symptoms, and autistic specific depression symptoms. Internal consistency of each subscale and total scores were excellent (.87 - .94). The ADAT-A was significantly correlated with related constructs including self-reported suicidality, defeat and entrapment ($r_s > .49$). The ADAT-A total score and subscales were significantly more strongly correlated with hypothesised proximally related compared to distally related constructs.

Limitations

The samples involved in the development and validation of the ADAT-A were largely female, and largely diagnosed as autistic in adulthood, which is not representative of the wider autistic population. The ADAT-A has initially been developed and validated for research purposes, and has not been validated for use in clinical contexts to screen for possible depression diagnosis.

Conclusions

The ADAT-A is a self-report autism specific depression assessment tool, developed and validated with and for autistic adults, without co-occurring intellectual disability. There is promising initial evidence in support of the measurement properties of this tool for use in research. Future research must explore whether the ADAT-A is useful in better identifying depression in autistic people in clinical settings, compared to other tools developed for the general population.

Introduction

A majority (79%) of adults diagnosed with autism (henceforth autistic adults [1–2]) meet diagnostic criteria for at least one co-occurring psychiatric condition at some point in their life, with depression and anxiety being the most

common [3]. High rates of depression in autistic people have been replicated across a number of studies [4–5]. However, autistic people can struggle to obtain an accurate and timely diagnosis of mental health problems such as depression [6], which can in turn affect access to appropriate treatment and support [7–8]. The consequences of undiagnosed and untreated depression is potentially devastating, given that depression is associated with increased risk of suicidal ideation, plans and attempts in autistic adults [9–11]. It is clearly vital to accurately identify depression in autistic people. However, systematic reviews have shown no depression assessment tools which have been developed or validated for autistic people [5, 12].

There are a number of reasons to believe that current depression assessment tools developed for the general population may not accurately identify depression in autistic people. One reason is that many characteristics of depression and autism overlap. For example, many autistic people experience difficulties with sleep, differences in emotional expression and communication, such as flat affect, and reduced eye contact – which are all also indicators of depression in the general population [13]. Depression assessment tools developed for the general population, are not able to tease apart these overlapping characteristics of autism and depression. This could mean that autistic people tend to score higher on depression assessment tools developed for the general population, even if they are not experiencing depression symptoms. Equally, autistic people may have depression symptoms erroneously attributed to being autistic, meaning that co-occurring depression may be more likely to go undiagnosed and untreated in autistic people [6–8].

Another reason that depression assessment tools developed for the general population may not accurately identify depression in autistic people, is different interpretation of items than intended by the tool designers. Previous research has shown that autistic people experience interpretation and response difficulties with a number of instruments designed for non-autistic people [14–17]. One component of this is differences in the cognitive characteristics of autistic people which may affect interpretation of items. For example, many autistic people tend to interpret language literally and have difficulty interpreting figures of speech [18], and items such as “feeling blue” in depression measures are therefore difficult for autistic people to successfully interpret and respond to. Autistic people can also experience difficulties in identifying and describing their own emotions (termed alexithymia) [19], which could also cause challenges in responding to items such as “feeling depressed or hopeless”. Another component is the lack of relevant items capturing the unique experiences of autistic people. For example, previous studies have shown that a suicidality measure developed for the general population is: a) interpreted and responded to differently by autistic compared to non-autistic people [14]; b) does not capture unique aspects of suicidality in autistic people, such as perseverate or “sticky” suicidal thoughts [14]; and c) when new items are included better capturing the unique aspects of suicidality relevant to autistic people, the new measure is more sensitive to detecting associations with relevant constructs compared to the original measure [20]. This suggests that adapting tools to make them clearer and more relevant to the unique experiences of autistic people will strengthen the evidence in support of the tools measurement properties in this group [12, 20, 21].

Previous research suggests that depression experienced by autistic people may have different characteristics and indicators compared to the general population, which are not captured in depression assessment tools developed for non-autistic people. For example, loss of interest in a previously intense interest [22–23] or agitation [24], and increase in difficulties commonly experienced by autistic people, such as in sleep difficulties, and social withdrawal [24]. Other autistic characteristics have also been associated with depression in autistic people. For example, depression symptoms have also been associated with sensory hyposensitivity in autistic children and young people [25–26], and camouflaging autistic traits in an attempt to fit in with others in autistic adults [27–28]. Depression assessment tools developed for the general population do not as yet include these other potential

indicators of depression in autistic people [12–13]. However, identifying and including these and other indicators could potentially improve identification of depression in autistic people [14–17, 20].

The current study therefore aimed to develop and validate a new depression assessment tool with and for autistic adults, for use in future research studies to facilitate our understanding of the potentially unique characteristics and risk markers for depression in autistic people. This is crucial to inform better assessment and treatment strategies for depression in this group. Previous research developing new tools, do not tend to test whether items are clear or relevant to the target population [12, 14]. However, ensuring content validity of a tool, with items interpreted and responded to as expected by the target population is a foundational measurement property on which all other measurement properties rely (COSMIN) [29]. The current study therefore undertook extensive consultation with autistic adults, to explore a) how autistic adults interpret and respond to a widely used and validated tool developed for the general population – the PHQ-9 [30]; b) whether any unique indicators of depression for autistic people were missing from the tool; and c) suggest and test new items addressing these interpretation and response issues, and missing items.

First, we hypothesised that the newly developed depression tool would return a three-factor structure, capturing cognitive/affective and somatic symptoms (as shown in previous research of depression tools in autistic adults) [31], and autistic depression symptomatology given the inclusion of autism specific items. Second, we hypothesised that the newly developed depression tool would show evidence for convergent validity, through medium to strong correlations with proximally related constructs capturing psychological distress (suicidality, defeat and entrapment) [32]. Further, the hypothesised factor and possible subscale of cognitive/affective symptoms would be particularly strongly correlated with these constructs. Third, we hypothesised that the newly developed depression tool would show evidence for divergent validity. Specifically, significantly stronger correlations with proximally related constructs (suicidality, defeat and entrapment) [32] compared to distally related constructs which have been associated more with anxiety than depression (camouflaging autistic traits and intolerance of uncertainty) [28, 33]. Further, the hypothesised factor and possible subscale of autistic specific depression symptoms may be particularly strongly correlated with autism specific constructs (camouflaging autistic traits).

Method

Design The study consisted of a development phase (see methods section describing development of ADAT-A), and a separate validation phase (reported in the results section of the current study). In the *Development Phase*: autistic adults completed two rounds of cognitive interviews (interview one $n = 15$; interview two $n = 9$); Development Survey One consisted of 251 autistic adults; Development Survey Two consisted of 448 autistic adults. The *Validation Phase* data reported in the results section of the current study consisted of 236 autistic adults.

Ethical Approval The research received a favourable ethical opinion from the relevant local Research Ethics Committees (ethics approval references P47603 and F1074), and was approved by the Coventry Autism Steering Group, who provided feedback on the cognitive interview schedule.

Participants The autistic group involved in the *validation phase* of the current study comprised 236 adults (87 male, 113 female, 33 non-binary, and 3 other gender, aged 18–61 years, mean age = 32.45, $SD = 11.18$) who self-reported a diagnosis of ASC from a trained clinician. Of these, 85 (36%) had an undergraduate degree and 58

(24.6%) a higher degree, 72 (30.5%) had a GCSE/A-level/College Diploma, 12 (5.1%) had no formal qualifications, and 9 (3.8%) preferred not to say; 50 (21.2%) participants were unemployed or unable to work. Participants were a community sample recruited from social media channels and the Autistica Network, a volunteers' database in the UK where autistic people register to receive invitations to take part in research studies.

Measures

Development of the Autistic Depression Assessment Tool - Adult

The ADAT-A was developed through iterative stages with autistic adults:

Cognitive Interviews: The first stage involved identifying interpretation and response issues and missing autism specific items in a widely used and well validated depression assessment (PHQ-9) [30] with 15 autistic adults. Cognitive interviews ensure that the target population interpret and respond to questions as the researchers intend, a crucial part of establishing content validity for a tool [34]. A comprehensive set of pre-prepared prompts were developed to identify and clarify problems in interpreting the PHQ-9 questions with autistic adults (see supplementary information for full interview schedule). This interview schedule was developed from three community and public involvement (CPI) focus groups convened as part of a public engagement event which discussed how to adapt mental health assessment tools for autistic adults (none of whom took part in the cognitive interviews). Each focus group consisted of seven participants: one facilitator, and equal representation of autistic adults, clinicians and researchers in each group. Each focus group member was given a copy of the PHQ-9, and the facilitator asked the group to discuss any potential problems autistic adults may have in interpreting the questions, and how these could be addressed. Each facilitator compiled up to five key points which were subsequently presented to all attendees for further discussion in a plenary session, with any additional points noted by the plenary chair. A subsequent focus group was held with the Coventry Autism Steering Group, who further discussed the main points raised at the public engagement event and provided feedback on the researcher's draft cognitive interview schedule. This ensured that the pre-prepared prompts were comprehensive, relevant and clear to autistic adults. Subsequently, 15 and 9 autistic adults took part in two rounds of cognitive interviews respectively to first identify potential issues in clarity, interpretation, and relevance of the PHQ-9 items, and second to test new and adapted items based on this feedback.

Online Development Surveys: Following the cognitive interviews, two online surveys were conducted to gather feedback on the PHQ-9 and further refine the ADAT-A with a larger sample of autistic adults. *Development survey one* consisted of 251 autistic adults who provided qualitative feedback and rated the clarity (yes/no) and importance (from 0 – 100) of each item of the PHQ-9 and adapted ADAT-A (234 diagnosed, 17 awaiting assessment; 30.7% male; mean age=41.91, $SD=13.44$; mean age of ASC diagnosis=36.09, $SD=14.03$; 61.4% Asperger Syndrome diagnosis). To ensure broad agreement for clarity/importance of individual items, retained items had to be rated at least 70/100 on clarity and importance. For those items rated below 70, the research team discussed the qualitative feedback and adapted the items to improve clarity. *Development survey two* asked autistic adults to complete and provide qualitative feedback on the PHQ-9 and revised ADAT-A (332 diagnosed, 117 awaiting assessment; 27.8% male; mean age=40.21, $SD=13.25$; mean age of ASC diagnosis=34.51, $SD=14.28$; 45% Asperger Syndrome/High Functioning Autism diagnosis). Subsequently, the research team met with an advisory group of 5 researchers, autistic people and those who support them, to address the qualitative feedback and finalise the ADAT-A items.

Autistic adults' feedback was incorporated to ensure that the retained items in the ADAT-A were both clear and relevant to autistic adults' experience of depression. Relevance of items were improved by: a) capturing change in behaviours from the individual person's baseline, which could indicate depression, but overlap with common experiences of autistic people (e.g. "more difficulties with sleep than usual"); and b) by including additional autism specific indicators of depression (e.g. "If you mask or camouflage, finding it more difficult than usual to do so"). Items were clarified by removing abstract language, splitting up multiple different options within a question into separate questions, and increased use of relevant examples within items. Participants can also choose whether or not to see visual aids for each item to help quantify abstract response options (e.g. somewhat, very). It is recommended that these visual aids are optional, given that many but not all autistic people said they found these useful.

Autistic Depression Assessment Tool - Adult

The ADAT-A has 21 items capturing depression symptoms in the past 14 days. The ADAT-A has staged questions for each symptom: 1) the presence (yes/no) of the difficulty in the past 14 days; 2) if present, the length of time the difficulty has been experienced for over the past 14 days (from 1-3 to 12-14 days); and 3) the impact of the symptom on everyday functioning (from "Never" (0) to "Extremely" (4)). Answering "no" to a difficulty is scored 0, length of time is scored from 1-4, and impact from 1-4. Scores across the sections are summed to obtain individual item scores from 0-8, with total scores ranging from 0-168, with higher scores indicating a greater number / impact of depressive symptoms in the past 14 days.

A set of 13 items were designed with feedback from autistic adults to capture depression symptoms according to DSM-V and ICD-10 criteria (anhedonia, sleep difficulties, exhaustion, changes in appetite, depression, hopelessness, restlessness or slowing down, concentration difficulties, suicidality). An additional set of 8 items were also developed, informed from previous literature and autistic adults' feedback. These additional items aimed to capture autism specific indicators of depression not currently included in previous depression measures (increased difficulties in social situations, increase in social withdrawal, increased difficulties in adapting to change, and increased sensory hyper-sensitivity).

The ADAT-A with complete scoring instructions is freely available from our group's website:

<https://sites.google.com/view/mentalhealthinautism/resources/measurement-tools>

Defeat and Entrapment Scale

The Defeat and Entrapment Scale (DES) [35] is a 16 item self-report scale designed to capture feelings of defeat (a failed social struggle), and entrapment (feeling as there is no escape route from one's current circumstances). Participants rate statements such as "I want to get away from myself", "I am in a situation I feel trapped in" (entrapment), and "I feel I have not made it in life", "I feel that I am not a successful person" (defeat), on a five-point scale from 1 "Not at all like me" to 5 "Extremely like me". The DES was developed and validated in a sample of university undergraduates and depressed patients, with evidence in support of factors capturing defeat and entrapment, excellent internal consistency for total scores and subscales, and convergent validity with related constructs (depression, hopelessness and social rank) [35]. However, the scale has not been validated in autistic adults. In the current study, Cronbach's alpha showed excellent internal consistency for the DES total scale $\alpha=.955$, defeat sub-scale $\alpha=.941$, entrapment sub-scale $\alpha=.911$.

Suicide Behaviours Questionnaire – Autism Spectrum Conditions

The SBQ-ASC is a self-report measure developed with and for autistic adults to capture suicidal thoughts and behaviours, based on extensive consultation through focus groups, cognitive interviews and online surveys with autistic adults [20]. The SBQ-ASC has 5 scored items. Item 1 assesses lifetime experience of suicidal thoughts and behaviours from “Never” (0) to “I have attempted to end my life” (4). Item 2 assesses frequency of intense suicidal thoughts in the last 12 months from “Never” (0) to “1 or more times a day” (6). Item 3 assesses perseverative intense suicidal thoughts from “Not Applicable” (0), “Less than 5 minutes” (1) to “More than 8 hours” (5). Item 4 assesses likelihood of suicide attempt from “Not Applicable” (0), “No chance at all” (1) to “Very likely” (5). A visual aid, such as a measuring jug or thermometer, is offered to participants to help quantify each response option for item 4 (e.g. “Very unlikely”, “Very likely”) if they think this could be useful to them. Item 5 assesses communication of future suicide intent and past suicide attempts to others. Responses are scored from “Not applicable” (0) / “No” (0), to “Yes, once” / “Yes more than once”. Endorsing either “Yes” item is scored 1 for suicidal thoughts, 2 for future suicide attempts, and 3 for past suicide attempts. Participants can endorse all the options giving a maximum score of 6 for item 5. Scores range from 0-26, with higher scores indicating higher levels of suicidal thoughts and behaviours. The SBQ-ASC has strong evidence in support of content validity, factor structure, internal consistency, test retest reliability, convergent and divergent validity in autistic adults [20]. In the current study, Cronbach’s alpha showed acceptable internal consistency for the SBQ-ASC total scale $\alpha=.671$

Camouflaging Autistic Traits Questionnaire (CAT-Q)

The Camouflaging Autistic Traits Questionnaire (CAT-Q) is a 25-item self-report questionnaire assessing the extent to which a person engages in social camouflaging behaviours, validated in autistic and non-autistic adults with equivalent factor structure between the groups [27]. The CAT-Q captures three domains of social camouflaging: (1) “compensation” (behaviours used to compensate for autism-related difficulties in social situations); (2) “masking” (behaviours used to hide autistic characteristics or present a non-autistic personality to others); and (3) “assimilation” (behaviours used to fit in better with others and not “stand out” from the crowd). Participants rate each of the 25 questions on a seven-point Likert scale between “Strongly Agree” to “Strongly Disagree”. Responses are scored between 1 and 7, with higher scores for items which endorse presence of social camouflaging behaviour. In the current study, Cronbach’s alpha for whole scale $\alpha=.903$, Compensation subscale $\alpha=.811$, Masking subscale $\alpha=.663$, Assimilation subscale $\alpha=.745$.

Intolerance of Uncertainty Scale – Short Form

The Intolerance of Uncertainty Scale – Short Form (IUS-12) [36] is a 12-item self-report questionnaire capturing a form of anxiety, where a person tends to react negatively to uncertain situations. Participants rate statements such as “Unforeseen events upset me greatly”, and “When I am uncertain I can’t function very well”, on a scale from 1 “Not at all characteristic of me” to 5 “Entirely characteristic of me”. Scores range from 1-60, with higher scores indicating higher levels of intolerance of uncertainty. However, this scale although widely used in studies of autistic people, has not yet been validated in this group [37]. In the current study, Cronbach’s alpha showed excellent internal consistency for the IUS-12 total scale $\alpha=.87$.

Demographics

Participants were asked to report on their age, gender, employment, highest qualification, and autism diagnosis.

Procedure

Participants were invited to complete an online survey, using Qualtrics, which aimed to better understand suicidality and mental health in autistic adults. Participants were informed that autistic adults 18-years or over could participate, regardless of experience of mental health problems or suicidal thoughts or behaviours. Participants were fully briefed about the nature of the research, that they could skip questions and sections of the survey that made them feel uncomfortable, stop the survey at any time and complete it later. Participants were also provided information about relevant support services before taking part in the study, after each section of the study, and after taking part in the study in a downloadable debrief sheet. After providing consent, participants completed the demographics questions, Camouflaging Autistic Traits Questionnaire (CAT-Q), Defeat and Entrapment Scale (DES), Intolerance of Uncertainty Scale – Short Form (IUS-12), Autistic Depression Assessment Tool – Adult (ADAT-A) and Suicide Behaviours Questionnaire – Autism Spectrum Conditions (SBQ-ASC). Subsequently participants were provided with a full debrief including information about further information and support, followed by a positive mood induction procedure (a doodle page with jokes, puzzles and cute animal videos) which has proved effective in previous research exploring similar topics [38].

Analyses

Analyses were conducted in SPSS version 26. 431 participants initially accessed the survey. Of these, 376 consented to take part in the study and 311 subsequently completed at least one measure. Of these 282 started the ADAT-A, and 236 (83.69%) completed the ADAT-A with no missing items. Visual inspection of the data showed no pattern to missing data. Where missing data accounted for less than 10% of the total number of items, missing items were imputed. No missing items were imputed for the ADAT-A as missing data for all 46 participants was >10% of the total number of items.

Exploratory Factor Analysis

Principle axis factoring analysis with Oblimin rotation was performed on the sample of 236 autistic adults who completed the ADAT-A. The sample size was sufficient for EFA, with over 7 participants per item, and over 100 participants total [29].

Reliability and Validity

Internal consistency was measured using Cronbach's alpha for total scores. SBQ-ASC, defeat and entrapment are designed to measure rare experiences [20,32]. Therefore, as with previous similar research [11,20] Spearman's correlations assessed convergent validity between the ADAT-A and measures of defeat, entrapment, and Suicidality (SBQ-ASC). Divergent validity was assessed using z-tests to compare the strength of the correlation coefficients. Specifically: a) whether the ADAT-A was significantly more strongly correlated with more proximal constructs (SBQ-ASC, defeat and entrapment) than more distally related constructs (CAT-Q, IUS-12); b) whether the autistic depression symptoms subscale of the ADAT-A was significantly more strongly correlated with an autism relevant construct (camouflaging autistic traits) compared to the cognitive/affective and somatic subscales of the ADAT-A; and c) whether the cognitive/affective subscale of the ADAT-A was significantly more strongly correlated with similar constructs capturing psychological distress (suicidality, defeat and entrapment), compared to the somatic and autistic depression subscales. Spearman r benchmarks for effect size: 0.1= small effect, 0.3= medium effect and 0.5= large effect [39].

Results

Exploratory Factor Analysis

Table 1 shows the results of the EFA which indicates evidence for a three-factor solution explaining 53.39% of the variance. All items of the ADAT-A were retained.

Reliability and Validity

Internal Consistency: Excellent internal consistency was found for each subscale and total scale: ADAT-A total $\alpha = .943$, autistic depression subscale $\alpha = .88$, cognitive/affective $\alpha = .86$, somatic $\alpha = .871$ (Table 1).

Convergent Validity: Convergent validity was explored in the sample of autistic adults who had completed the ADAT-A and at least one other measure ($n=235$). Spearman's correlations showed that ADAT-A total scores were significantly correlated with defeat ($r_s = .586$), entrapment ($r_s = .634$) and suicidality ($r_s = .492$) with medium-strong effect size (Table 2).

Divergent Validity: Table 2 shows results of all inter-correlations between variables. In the sample of autistic adults who had completed the ADAT-A, SBQ-ASC and CAT-Q ($n=165$), the ADAT-A was significantly more strongly correlated with the SBQ-ASC ($r_s = .498$), than the CAT-Q ($r_s = .334$) ($z=1.754, p=.04$). In the sample of autistic adults who had completed the ADAT-A, SBQ-ASC and IUS-12 ($n=168$), the ADAT-A was more strongly correlated with the SBQ-ASC ($r_s = .492$), than the IUS-12 ($r_s = .368$) but this difference was not statistically significant ($z=1.476, p=.07$). In the sample of autistic adults who had completed the ADAT-A, defeat scale and CAT-Q ($n=227$), the ADAT-A was significantly more strongly correlated with the defeat scale ($r_s = .582$), than the CAT-Q ($r_s = .336$) ($z=3.52, p<.001$). In the sample of autistic adults who had completed the ADAT-A, defeat scale and IUS-12 ($n=230$), the ADAT-A was significantly more strongly correlated with the defeat scale ($r_s = .586$) than the IUS-12 ($r_s = .332$) ($z=4.178, p<.001$). In the sample of autistic adults who had completed the ADAT-A, entrapment scale and CAT-Q ($n=226$), the ADAT-A was significantly more strongly correlated with the entrapment scale ($r_s = .63$), than the CAT-Q ($r_s = .324$) ($z=4.735, p<.001$). In the sample of autistic adults who had completed the ADAT-A, entrapment scale and IUS-12 ($n=229$), the ADAT-A was more strongly correlated with the entrapment scale ($r_s = .634$), than the IUS-12 ($r_s = .328$) ($z=5.265, p<.001$).

In the sample of autistic adults who completed the ADAT-A and CAT-Q ($n=233$), the CAT-Q was significantly more strongly correlated with the autistic depression subscale of the ADAT-A ($r_s = .414$) than with the somatic subscale ($r_s = .29$) ($z=2.781, p<.01$) and the cognitive/affective subscale ($r_s = .169$) ($z=4.723, p<.001$). In the sample of autistic adults who completed the ADAT-A and SBQ-ASC ($n=168$), the SBQ-ASC was significantly more strongly correlated with the cognitive/affective subscale of the ADAT-A ($r_s = .51$) than with the somatic subscale ($r_s = .438$) ($z= 1.708, p=.04$) and the autistic depression subscale ($r_s = .395$) ($z= 2.04, p=.02$). In the sample of autistic adults who completed the ADAT-A and defeat scale ($n=230$), the defeat scale was significantly more strongly correlated with the cognitive/affective subscale of the ADAT-A ($r_s = .632$) than with the somatic subscale ($r_s = .485$) ($z= 3.418, p<.001$), and the autistic depression subscale ($r_s = .495$) ($z= 2.67, p<.01$). In the sample of autistic adults who completed the ADAT-A and entrapment scale ($n=229$), the entrapment scale was significantly more strongly correlated with the cognitive/affective subscale of the ADAT-A ($r_s = .633$) than with the somatic subscale ($r_s = .497$) ($z= 3.179, p<.001$), but not the autistic depression subscale ($r_s = .6$) ($z= .673, p=.25$).

Discussion

To our knowledge, no depression assessment tool has been specifically designed with and for autistic adults, to capture experiences of depression not included in depression assessment tools developed for the general population [5,12]. Development of the ADAT-A was informed through three focus groups, 24 interviews, and two large online surveys, to acquire feedback on interpretation and response issues experienced by autistic adults when completing a widely used and validated tool developed for the general population (PHQ-9) [30], and three iterations of the ADAT-A, to ensure that the finalised items were clear and relevant to autistic adults.

Autistic adults' qualitative feedback from the focus groups, cognitive interviews and online surveys were very consistent regarding interpretation and response issues to a widely used and validated depression assessment tool developed for the general population (PHQ-9) [30]. Autistic adults reported that many items overlapped with their typical experiences of being autistic, such as sleep difficulties, difficulties in concentration, appetite, speaking or moving slowly in a way noticed by others – therefore they may rate these items highly without necessarily feeling depressed. However, many autistic adults commented that when they experience depression, they experience these difficulties more than usual. For example, always having had difficulties with sleep and concentration, but these becoming more pronounced and having more of an impact on their daily lives when depressed. Autistic adults also commented that there was a lack of autism relevant items that captured their unique experiences of depression, such as becoming more socially withdrawn, finding it more difficult than usual to cope in social situations, camouflage, cope with change, losing interest in a previously intense interest, increase in sensory sensitivity, and desire to self sooth through stimming more than usual. Autistic adults also reported difficulties in interpreting and responding to the items, to an extent which caused anxiety in not knowing exactly how to answer completely truthfully and accurately. One main aspect was trying to quantify the abstract response scale (e.g. “nearly everyday”), another was difficulty interpreting exactly what was meant by “in the last 2-weeks”, difficulty with figures of speech in items (such as “feeling down”), complex language (for example where an item included two or more different clauses), and trying to imagine how others see them (e.g. “so others could have noticed”).

These results are consistent with previous research. Generally, autistic adults experience difficulties across a number of questionnaires designed for the general population [14-17]. Consistent issues identified in previous research and replicated in our study include: 1) complex or abstract language or figures of speech; 2) imprecise response options; 3) anxiety related to not being able to answer completely truthfully or with full accuracy; and 4) lack of autism relevant items capturing their unique experience [14-17]. This is consistent with what we know about the different ways autistic people can interpret information, such as tending to interpret language literally [18], difficulties identifying and describing one's thoughts and emotions (termed Alexythymia) [19], imagination, and interpreting other's thoughts and feelings [40].

The ADAT-A was therefore designed to address these common interpretation and response difficulties and improve the clarity and relevance of the depression assessment tool with and for autistic adults. The ADAT-A therefore included: 1) autistic specific signs of depression identified through consultation with autistic adults; 2) a new response scale to more accurately capture change in symptoms from an individual's baseline (to better distinguish common difficulties experiences by autistic people from indicators of depression), and subsequently rate the impact of these symptoms on an autistic person's everyday life; 4) simplifying complex language and multi-clause sentences; 5) staging questions, so participants only rate the length of time and impact of those difficulties they have actually experienced; 6) clarifying the rating scales by including the exact number of days, and if useful, visual aids to help quantify abstract response options (e.g. “Somewhat”). These recommendations from autistic adults are consistent with previous research. For example, capturing change in difficulties commonly experienced

by autistic people [13], and capturing autism specific indicators of depression, such as agitation and increased social withdrawal [24].

There was evidence in support of a range of measurement properties of the ADAT-A. As predicted, exploratory factor analysis showed support for three constructs captured by the ADAT-A with excellent internal consistency for each of these three subscales (all $\alpha > .8$). First, a somatic cluster of depression symptoms (e.g. fatigue, sleep difficulties, restlessness, changes in appetite), second a cognitive/affective cluster of depression symptoms (e.g. anhedonia, depression, hopelessness, suicidality), and third a cluster of symptoms indicating autism specific depression symptoms (social withdrawal, increased sensory sensitivity, restlessness, increased difficulties in coping with change, social situations, and increased difficulties with camouflaging). There was also support for convergent validity of the ADAT-A with proximally related constructs capturing psychological distress, with medium-strong correlations with suicidality, defeat and entrapment. These results suggest that the ADAT-A is able to capture different dimensions of depression in autistic adults which are associated with other related constructs.

Previous research has shown that by increasing the clarity and relevance of mental health assessment tools with and for autistic adults improves the sensitivity of the tool to detect associated constructs (Cassidy et al. under review). Results from the current study showed consistent evidence in support of the ADAT-A being sensitive to detect differences in the strength of associations with proximal compared to more distally related constructs. Specifically, the ADAT-A was significantly more strongly correlated with proximal constructs capturing psychological distress (suicidality, defeat and entrapment) compared to more distally related constructs more associated with anxiety (camouflaging autistic traits and intolerance of uncertainty) [28,33]. The autistic depression subscale was also significantly more strongly correlated with an autism relevant construct (camouflaging autistic traits) compared to the somatic or cognitive/affective subscales. The cognitive/affective subscale of the ADAT-A was significantly more strongly correlated with other constructs capturing psychological distress (suicidality and defeat), compared to the somatic and autistic depression subscales. Interestingly, entrapment was significantly more strongly correlated with the cognitive/affective subscale of the ADAT-A than the somatic subscale, but there was no significant difference between the strength of the correlation between entrapment and the cognitive/affective and autistic depression subscales of the ADAT-A.

These results suggests that the ADAT-A could be particularly useful in future studies attempting to model proximal and distal risk factors for depression in autistic people. Further, the different subscales of the ADAT-A could be particularly useful in identifying different risk factors for different subcomponents of depression in autistic people. Specifically, the autistic depression symptoms component is particularly sensitive to detecting autism specific risk markers for depression, such as camouflaging. Whereas the cognitive/affective subscale could be most useful for exploring associations with constructs related to psychological distress, such as suicidality and defeat. Entrapment correlated most highly with both the cognitive/affective and autistic depression subscales of the ADAT-A. This could reflect the fact that entrapment is a form of psychological distress, but could also be related to increased difficulties in cognitive flexibility common amongst autistic people [41], which is also captured in the autistic depression subscale of the ADAT-A. Hence, the ADAT-A could be extremely useful in developing a much more nuanced understanding of what factors are associated with difference aspects of depression in autistic people, to better inform diagnosis, treatment and prevention strategies.

One could question the utility or need of developing specific mental health assessment tools with and for autistic people. For example, the ADAT-A has not been developed for, or validated in, non-autistic people, and inclusion of autism specific depression indicators will likely mean that this tool is not appropriate for assessment or

measurement of depression in non-autistic people. However, availability of autism specific mental health assessment tools such as the ADAT-A allows for exploration of much more important questions beyond “are autistic more at risk of depression than the general population”, to “why are autistic people more at risk of depression, and what can be done to reduce this risk?”. The ADAT-A in particular has promising initial evidence in support of exploring different associations with different subcomponents of depression in autistic people, never before captured in any other depression assessment tools. Future research must further explore how the subcomponents of the ADAT-A are associated with different constructs which may be associated with depression in autistic people, such as autistic burnout [42], sensory hyposensitivity [25-26], social stigma and identity [43-44], and the double empathy problem [45-46].

There are clear implications for clinical practice. First, our wide consultation with autistic people, development and initial validation of the ADAT-A, provides a new assessment tool to identify unique features of depression in autistic adults. Clinicians should be aware that changes in difficulties commonly experienced by autistic people could be a very important sign of depression in this group. However, the current study only tested the potential usefulness of the ADAT-A in research. Future work will need to explore the usefulness of the ADAT-A in clinical practice and tracking response to change over time in treatment studies.

A key strength and novel aspect of this study was the involvement of autistic people in identifying interpretation and response issues in a widely used and validated depression assessment tool developed for the general population, and from this, co-producing a new autism specific depression assessment tool. Assessing the appropriateness and measurement properties of the ADAT-A followed recommended best practice according to a validated research tool used to assess the quality of evidence for and against the measurement properties of health outcome assessment tools (COSMIN) [29]. For example, COSMIN argues that content validity is the most important foundational property on which all other measurement properties rely on – if a tool is not relevant or clear to the target group, then it is unlikely to adequately capture the intended construct in that group. Despite this, few studies conduct extensive work to establish content validity of tools in groups, using rigorous methods such as participatory approaches or cognitive interviewing [14-17,20]. In contrast, we conducted extensive work to ensure that the adapted ADAT-A captured the unique experience of depression in autistic adults, prior to finalising the tool and assessing its measurement properties in this group. As with previous similar research using this approach [20], results suggest that ensuring content validity helps ensure the sensitivity of the new tool to detecting associations with relevant constructs.

Limitations

The samples involved in developing and validating the ADAT-A were autistic adults, without co-occurring intellectual disability, who had largely been diagnosed in adulthood, or who were awaiting an autism diagnosis. Therefore, the ADAT-A may need further testing and possible adaptation in autistic people diagnosed in childhood, and autistic people with co-occurring intellectual disability. The study sample included a high proportion of females, which is not representative of the wider autistic population which is largely male [47]. Autism diagnosis was based on self-report. The ADAT-A has been initially developed and validated for use in research, and it will be important for future work to explore the usefulness of this new tool for identifying depression in autistic adults in clinical practice. The current study assessed initial factor structure using exploratory factor analysis, and future research is needed to conduct confirmatory factor analysis, further hypothesis testing, and explore other measurement properties, such as test retest reliability. It is also important to note that further work will be

necessary to develop a range of depression and mental health assessment tools appropriate for different subgroups and contexts, including autistic children and youth, with or without intellectual disability, in research and clinical practice, given that tools are not valid or invalid, but rather developed and validated for use in different contexts [12,21,48].

Conclusion

We present a new autistic depression assessment tool (ADAT-A) developed and validated with and for autistic adults, to more accurately capture depression in this group. The ADAT-A has evidence in support of a range of measurement properties, including content validity, structural validity, internal consistency, convergent and divergent validity. The ADAT-A shows promise for furthering our identification of unique risk factors for different components of depression in autistic adults, to inform new treatment and intervention strategies to reduce the high rates of depression in this group. Further, the ADAT-A could also be useful in clinical practice to help accurately identify depression in autistic people, addressing a number of interpretation, response and measurement issues in current depression assessment tools developed and validated for the general population.

Abbreviations

ADAT-A = Autistic Depression Assessment Tool – Adult Version; ASC: Autism Spectrum Condition; CAT-Q: Camouflaging Autistic Traits Questionnaire; COSMIN: Consensus-based standards for the selection of health measurement instruments; DES = Defeat and Entrapment Scale; EFA: Exploratory Factor Analysis; IUS-12 = Intolerance of Uncertainty Scale – 12 Item; GCSE = General Certificate of Secondary Education; PHQ-9: Patient Health Questionnaire – 9 Item; SBQ-ASC: Suicide Behaviours Questionnaire – Autism Spectrum Conditions; SPSS = Statistical Package for the Social Sciences.

Declarations

Authors contributions

SAC and JR contributed to the conception of the study. All authors contributed to the design of the study. SAC, JG, LB and HCW contributed to data collection and analysis. SAC, JR, LB and HCW contributed to the design and wording of the ADAT-A. SAC wrote the draft manuscript, and JR, JG, LB and HCW critically reviewed and approved the manuscript prior to publication.

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Availability of data and materials

The dataset used and analysed in the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Ethics approval for this study was obtained through the institutional Human Research Ethics Committee. Informed consent was obtained from all individual participants included in the study.

Participants were provided information pertaining to the study via a Plain Language Statement, which was presented to them before commencing the study. All participants provided informed consent by reading the participant information sheet and completing a consent form (online or in person).

Consent for publication

Not applicable. All participant information and data are anonymous.

Competing interests

The authors declare they have no competing interests.

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Tables

Table 1
Item level factor loadings for the exploratory factor analysis in the autistic group.

| ADAT-A Items | Somatic | Autistic | Cognitive/Affective |
|--|---------|----------|---------------------|
| 1. Lack of interest in doing the things you usually enjoy. | .345 | -.156 | .683 |
| 2. If you usually have a strong interest in a particular topic or activity, is this less than usual? | .293 | -.003 | .503 |
| 3. Being tearful or wanting to cry. | .135 | .206 | .351 |
| 4. Feeling hopeless. | -.043 | .041 | .86 |
| 5. Feeling depressed (such as feeling sad or 'down'). | -.001 | .077 | .791 |
| 6. More difficulties with sleep than usual. | .373 | .114 | .156 |
| 7. You feel more mentally or physically exhausted than usual after an average day. | .775 | .179 | -.076 |
| 8. You feel more tired than usual, but with no change in activity level. | .714 | .125 | -.002 |
| 9. You have less mental or physical energy than usual to cope with everyday life. | .675 | .019 | .172 |
| 10. If attending social events, you need more time than usual to recover afterwards. | .162 | .426 | .231 |
| 11. Changes in your appetite. | .296 | .157 | .239 |
| 12. More difficulty than usual concentrating on an activity you enjoy, even when it is quiet and there are no distractions. | .615 | -.068 | .256 |
| 13. Feeling more fidgety, or desire to 'stim' more , or more restless than usual. | .228 | .465 | -.031 |
| 14. Moving or speaking more slowly than usual. | .349 | .255 | .058 |
| 15. Thoughts or attempts of ending your life. | -.034 | .189 | .623 |
| 16. More difficulty coping in social situations than usual. | .107 | .597 | .197 |
| 17. Avoiding social situations more than usual. | .066 | .535 | .165 |
| 18. If you mask or camouflage, finding it more difficult than usual to do so. | .194 | .61 | .002 |
| 19. More upset than usual when things don't go to plan. | -.073 | .739 | .129 |
| 20. Desire for things stay the same more than usual. | -.101 | .743 | -.019 |
| 21. Being more sensitive to the sensory aspects of your environment than usual. | .164 | .545 | -.069 |
| Chronbachs Alpha | .871 | .88 | .886 |

Table 2
Spearman inter-correlations between all variables in the autistic group.

| Autistic and Possibly Autistic Group | CAT-Q | Defeat | Entrapment | IUS-12 | SBQ-ASC | ADAT-A | Somatic | Autistic |
|--------------------------------------|---------|---------|------------|---------|---------|---------|---------|----------|
| Defeat | .203** | | | | | | | |
| Entrapment | .296*** | .750*** | | | | | | |
| IUS-12 | .463*** | .406*** | .431*** | | | | | |
| SBQ-ASC | .16* | .438*** | .494*** | .211** | | | | |
| ADAT-A | .33*** | .586*** | .634*** | .335*** | .492*** | | | |
| Somatic | .29*** | .485*** | .497*** | .232*** | .438*** | .921*** | | |
| Autistic | .414*** | .495*** | .6*** | .391*** | .395*** | .894*** | .73*** | |
| Cognitive/Affective | .169** | .632*** | .633*** | .268*** | .51*** | .877*** | .762*** | .651*** |

*** $p < .001$; ** $p < .01$; * $p < .05$. CAT-Q = Camouflaging Autistic Traits – Questionnaire; IUS-12 = Intolerance of Uncertainty Scale – 12 Item; SBQ-ASC = Suicide Behaviours Questionnaire – Autism Spectrum Conditions; ADAT-A = Autistic Depression Assessment Tool – Adult.

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