RESEARCH ARTICLE

Development of the Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD)

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Many children with autism spectrum disorder (ASD) experience high levels of anxiety. A widely used measure for typically developing children is the Revised Child Anxiety and Depression Scale (RCADS). However, such anxiety measures may require adaptation to accommodate characteristics of those with ASD. An adapted version of the RCADS was created based on empirical evidence of anxiety phenomenology in ASD, which included additional items related to sensory anxiety, intolerance of uncertainty, and phobias. Content validity was refined during focus groups with parents. Polychoric factor analysis was undertaken on data from 170 children with ASD, aged 8-16, and their parents. This process resulted in the creation of a new 24 item scale (self and parent report) each with four subscales: Performance Anxiety, Uncertainty, Anxious Arousal, and Separation Anxiety, with evidence of good reliability and validity. The freely available Anxiety Scale for Children - ASD, Parent and Child versions (ASC-ASD) has promising psychometric properties including good internal consistency, validity, and 1 month test–retest reliability. ***Autism Res*** *2016, x:xxx–xxx*. & 2016 International Society for Autism Research, Wiley Periodicals, Inc.

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Introduction

Anxiety is common in young people with autism spectrum disorder (ASD). Between 22 and 84% of children are reported by parents to experience impairing anxiety [van Steensel, Bögels, & Perrin, 2011; White, Ollendick, Scahill, Oswald, & Albano, 2009]. Anxiety can have wide-ranging consequences, impacting on activities of daily living, quality of life, school attendance, and attainments; this in turn leads to difficulties for relatives [Leyfer et al., 2006]. It is of critical importance to understand the ways in which anxiety manifests and impacts on the lives of young people with ASD and to evaluate accurately the effectiveness of anxiety interventions.

The phenomenology of anxiety in ASD appears to be associated with a range of ASD characteristics including sensory processing abnormalities [Ben-Sasson et al., 2008; Green & Ben-Sasson, 2010; Lidstone, Uljarevic et al., 2014; Wigham et al., 2015], restricted and repetitive behaviours [Gerrard & Rugg, 2009; Rodgers, Glod et al., 2012a; Rodgers, Riby, Janes, Connolly, & McConachie, 2012b; Wigham, Rodgers, et al., 2015] and impairments in social functioning [Bellini, 2004]. Thus, young people with ASD may be predisposed to specific forms of anxiety due to a range of ASD factors, which should be taken into account during the assessment of their anxiety.

Furthermore, characteristic behaviours of ASD and symptoms of anxiety may overlap and prove difficult to delineate [Gjevik, Eldevik, Fjaeran-Granum, & Sponheim, 2011]. For example, repetitive behaviours and interests may be difficult to differentiate from the compulsive behaviours found in obsessive compulsive disorder (OCD) [Zandt, Prior, & Kyrios, 2009]. In addition, the overlap between some ASD-related characteristics (e.g., social withdrawal) and aspects of social anxiety mean that traditional conceptualisations of social anxiety may need to be reformulated in ASD [Hallett, Lecavalier et al., 2013a; Hallett, Ronald et al., 2013b; Kuusikko et al., 2008; Pellecchia et al., 2015]. In typically developing children, social anxiety may stem from fear of negative evaluation by others, whereas in ASD anxiety in social situations may stem from concerns relating to the violation of logical rules or the unpredictability of the social environment [Bolling et al., 2011a,b; Kerns et al., 2014; Zainal et al., 2014]. Similarly, in typically developing children, school refusal is a feature of separation anxiety; however, in children with ASD reluctance to go to school may stem from

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other anxieties regarding the school environment, including sensory overload or inability to engage in preferred routines, rather than separation from parents per se. Anxiety in children with ASD may, therefore, differ in important ways from traditional conceptualisations, limiting the reliability and validity of measurement with tools designed for typically developing children.

There is an emerging literature about the suitability of measures of anxiety for use with individuals with ASD. Kerns et al. [2014] examined anxiety presentations in young people with ASD and concluded that there was evidence for varied manifestations of anxiety in ASD. In their sample, 17% of children presented with "traditional" anxiety, 15% presented with anxiety altered in its presentation by its interaction with ASD-related characteristics, and 31% presented with a combined profile. White, Lerner et al. [2015] examined the metric and latent factor equivalence of the Multidimensional Anxiety Scale for Children (MASC-C) across three groups: young people with an anxiety disorder, young people with ASD and a healthy control group, and concluded that the factor structure was different in the ASD group, further supporting the notion of the varied manifestations of anxiety in ASD.

Lecavalier, Wood et al. [2014] systematically reviewed 10 anxiety measures for use in clinical trials in ASD. Four tools were considered as "*appropriate with conditions"*; the Child and Adolescent Symptom Inventory – 4th edition Revised [CASI-4R; Gadow & Sprafkin, 2002; Hallett et al., 2013a]; Multidimensional Anxiety Scale for Children [MASC; March et al., 1997]; Pediatric Anxiety Rating Scale [PARS; Ginsburg et al., 2011], and the Anxiety Diagnostic Interview Scale for DSM IV [ADIS; Silverman & Albano, 1996]. The authors concluded that using outcome measures developed for use with typically developing children "*may be less than satisfactory*" with young people with ASD. Wigham and McConachie [2014] undertook a systematic review of the measurement properties of outcome tools used in trials of cognitive behavioural therapy for anxiety in children with ASD. Three questionnaire measures were considered *robust*: The Spence Children's Anxiety Scale [SCAS; Spence, 1998], the Revised Children's Anxiety and Depression Scale [RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000], and the Screen for Child Anxiety Related Emotional Disorders [SCARED; Birmaher et al., 1999]. The authors urged caution in the use of tools developed to assess anxiety in typically developing children, with children who have ASD. This evidence suggests that the direct application of tools developed with typically developing children is unlikely to be appropriate for the measurement of anxiety in young people with ASD. It is important to consider why this may be the case and what changes may be required to current assessment tools.

While there may be significant gaps in the ways in which current tools are able to capture the phenomenology of anxiety in ASD, there is also evidence that traditional formulations and assessment of anxiety may be helpful in contributing to our understanding of anxiety in those with ASD. Indeed Kerns et al. [2014] reported that in their sample, 17% of young people with ASD presented with classic anxiety symptoms; and the reviews of standard anxiety tools [Lecavalier et al., 2014; Wigham & McConachie, 2014] indicate that they are acceptable, though not as good as they could be, for use with young people with ASD.

We propose, therefore that, rather than developing a measure from first principles, an adaptation, extension, and evaluation of a standard measure of anxiety for use with children with ASD would be the most appropriate next step. We chose to adapt the Revised Children's Anxiety and Depression Scale [RCADS; Chorpita et al., 2000], a 47 item measure of anxiety and depression with 6 subscales: panic, separation anxiety, OCD, generalised anxiety disorder (GAD), and social phobia and depression. The RCADS is the measure of anxiety used by many UK National Health Service clinical teams (e.g., Improving Access to Psychological Therapies teams www.cyiapt.org) and has been shown to have good psychometric properties in typically developing and clinical samples [Chorpita & Daleiden, 2002; Chorpita, Moffitt, & Gray, 2005; de Ross, Gullone, & Chorpita, 2002; Ebesutani et al., 2011]. The RCADS was considered a robust measure in the recent review of anxiety measures for use in ASD by Wigham et al. [2014]. An examination of its use with children with ASD indicated that the RCADS is moderately psychometrically acceptable but also highlighted room for improvement in terms of validity [Sterling et al., 2014].

As well as investigating the suitability of the original RCADS items, to bridge some of the gaps in the current assessment of anxiety in ASD we planned to adapt the measure by including items relating to three additional anxiety related constructs and so try to capture the ASD specific presentations of anxiety referred to in the literature. The first two constructs were based on established relationships between anxiety and ASD-related phenomena: sensory hypersensitivity [Ben-Sasson et al., 2008; Green & Ben-Sasson, 2010; Lidstone, Uljarevic et al., 2014; Reynolds & Lane, 2009; Wigham et al., 2015]; and intolerance of uncertainty [Boulter, Freeston, South, & Rodgers, 2014; Chamberlain et al., 2013; Wigham et al., 2015]. It is proposed that difficulty tolerating uncertainty in individuals with ASD results in increased engagement in repetitive behaviours in an attempt to impose predictability in the face of the intolerable uncertainty. Specific phobias are estimated

to be the most common anxiety subtype in ASD [Gjevik et al., 2011; Leyfer et al., 2006; Mattila et al., 2010; Witwer & Lecavalier, 2010]. Prevalence rates varied widely between 13% [Mazefsky et al., 2011] and 67% [Witwer & Lecavalier, 2010], although phobia questions are not often not included within anxiety measures.

The aims of this study were: In Stage one, in consultation with parents of children with ASD, to modify the RCADS and incorporate items related to three additional anxiety constructs (uncertainty, sensory hypersensitivities, and phobias). In Stage two, pilot the adapted measure with a representative sample of children with ASD and their parents, and investigate its factor structure, reliability and validity.

Method

Stage 1

Method. The wording of 37 original RCADS anxiety items (not including the 10 depression items) was modified based on interviews with parents of young people with ASD about their interpretation of the items [Jamieson, unpublished thesis].

Additional items were created relating to anxiety associated with sensory processing, uncertainty, and phobias. Uncertainty items were selected from the Intolerance of Uncertainty Scale [Freeston, Rhéaume, Letarte, Dugas, & Ladouceur, 1994]. Sensory items were based on the Short Sensory Profile (SSP) [Dunn, 1999] and phobia items were selected from a survey of parents of children with ASD recruited from the Dasl^{n}e database [McConachie et al., 2009; Warnell et al., 2015].The format for scoring and layout of questions for the new measure was retained from the original RCADS with each items rated from 0 to 3, where 0 = Never, 1 = Sometimes, 2 = Often, and 3 = Always. There was a total of 79 items in the initial adapted version. Consultation regarding the content of the draft measure was then undertaken with parents. Newcastle University ethics committee provided a favourable ethical opinion for this consultation work. All participants provided informed consent.

Consultation. Twelve parents were recruited from the local branch of the National Autistic Society. The consultation group lasted 2.5 hours and involved two tasks Participants were divided into two groups and provided with a flip chart, pens, and sticky tape. All discussions were audio recorded. The groups were provided with a series of laminated cards each including an original item from the RCADS and definitions in everyday language of panic, separation anxiety, OCD, GAD, and social phobia. Participants were asked to briefly discuss each item and, thinking about a child they know who has ASD, consider what type of anxiety or concerns the item made them think of. They were then asked to allocate each item to the anxiety type that they thought best captured the anxiety being measured *for a child with ASD*, putting any that they were not sure of in the "don't know" pile. Finally, participants were asked to take any items they had allocated to the "don't know" pile and discuss the wording and how the items could be improved to make them less ambiguous. The goal of this task was to determine whether there was any ambiguity in wording.

Participants were then provided with the new anxiety items relating to uncertainty, sensory hypersensitivities, and phobias and were asked to select those items that best reflected experiences for young people with ASD that they knew. Based on parent feedback amendments to wording were made to some of the new items. The consensus from the participants was that all the proposed new items were appropriate and relevant, and all were retained for Stage 2.

New items were then randomly placed among the original RCADS items and the 10 depression subscale items added, creating a parent report measure with 76 items, and a 74 item child measure. A Flesch–Kincaid readability test on the child version produced a score of 86, indicating suitability for an average reading age of 9 years and above.

Stage 2

Method. The two new versions of the measure (child and parent) were sent by post to participating families. To evaluate test–rest reliability, parents and children were asked to complete the new measure again 1 month after initial data collection. A favourable ethical opinion was provided by London-Westminster NRES Committee (Ref. 14/LO/0473) for the postal survey.

Participants. Participants included children with ASD diagnosed by UK National Health Service multidisciplinary teams and their parents. Recruitment of participants was via two ASD-related databases hosted by Newcastle University (Dasl^{n}e) and ASD-UK [McConachie et al., 2009; Warnell et al., 2015; Wood et al., 2015]. Dasl^{n}e recruits families from NHS diagnostic teams in the North East UK and the representativeness of the children with ASD was found to be acceptable in terms of gender and socioeconomic status [McConachie et al., 2009]. ASD-UK recruits from NHS teams from across the rest of the UK; families and children participating have been shown to be representative of UK families with children with ASD based on a comparison of those choosing and those not choosing to participate, and participant characteristics compared with population samples; children included were found to

have valid ASD diagnoses [Warnell et al., 2015]. Database families were contacted if their children were aged between 8 and 15 years with fluent speech. Exclusion criteria were children 7 years of age or below, or 16 years and above (due to the suitability of the measures), or those with a co-morbid condition, which affected their capacity to consent.

Procedure. The study information sheets, consent forms, questionnaires, and stamped addressed envelopes were posted to the families with a covering letter. Participants were asked to sign consent forms and return these with their completed questionnaires, if they wished to participate.

Measures. Children were asked to complete the child version of the adapted measure – and The Screen for Anxiety and Related Emotional Disorders (SCARED) – Child version.

In addition to the parent version of the adapted measure, parents were asked to complete the following measures.

The repetitive behaviour questionnaire. The repetitive behaviour questionnaire (RBQ) is a 33 item measure of repetitive behaviours [Honey, McConachie, Turner, & Rodgers, 2012; Turner, 1995]. It is a caregiver report of repetitive sensory motor and insistence on sameness behaviours, comprising 30 items with 3 or 4 frequency and severity response options. The RBQ has been found to have good construct and concurrent validity in children with ASD [Honey et al., 2012] and a relationship has been found between repetitive behaviours and anxiety in ASD [Rodgers, Riby et al., 2012b].We hypothesised that the RBQ would correlate with the new adapted measure providing a measure of convergent validity.

Short sensory profile. The SSP is a 38-item measure of sensory behaviours and is a caregiver report of children's sensory symptoms and responses to sensory experiences in daily living. Items are rated on a five-point frequency scale. Normative scores are available and good internal consistency across the subscale and total scores ($\alpha = 0.70$–0.90) has been found by the instrument's authors. The total score is an indicator of the level of abnormality in overall sensory processing, with lower scores indicating greater impairment and more sensory abnormalities. We hypothesised that sensory over responsiveness subscale total score would correlate with the new adapted measure providing a measure of convergent validity [McIntosh, Miller, & Shyu, 1999].

Strengths and difficulties questionnaire. The Strengths and difficulties questionnaire (SDQ) is a 25 item informant report measure of psychological well-being for children aged 3–16 years (www.sdq.info.org). It has five subscales: four pertaining to problem behaviours (emotional, conduct, hyperactivity, and peer problems), which can be added to create a "total difficulties" score; and one subscale pertaining to prosocial behaviours. Each subscale comprises five questions with three Likert type response options: "not true"; "somewhat true"; and "certainly true." Internal consistency ($a = .73$) and re-test reliability (.62) in a general population samples have been reported [Goodman, 2001]. We hypothesised that the Emotional subscale would correlate with the new adapted measure providing a measure of convergent validity [Goodman, 1997].

The screen for anxiety and related emotional disorders. The SCARED is a 41 item measure of anxiety. We hypothesised that the total score of the SCARED would correlate with the total score of the new adapted measure providing a measure of criterion validity.

Child depression inventory CDI-2. The Child depression inventory (CDI-2) [Kovacs, 2011] is a 17 item parent report measure of depressive symptoms in children. We hypothesised that discriminant validity will be demonstrated by a stronger relationship between new anxiety measure and the SCARED than between the new measure and the CDI.

Analyses. ASC-ASD questionnaires were excluded if more than 10% of responses were missing. Missing values on the ASC-ASD were replaced prior to factor analysis with the mean for that participant based on their total score, where 10% or fewer items were missing. The same method was used with the other measures unless the guidelines in a manual suggested otherwise. For the SSP the mean was imputed for a subscale if no more than one item was missing on that subscale; the remainder were excluded.

The sample size was calculated based on our intention to undertake factor analyses, for which a sample of 100–200 is recommended when the relationship between factors is not established [Guadagnoli & Velicer, 1988; MacCallum, Widaman, Zhang, & Hong et al., 1999]. According to criteria developed to assess the methodological quality of reports on assessment measures (COSMIN: COnsensus-based Standards for the selection of health status Measurement INstruments) where $N = >100$ this is excellent for internal consistency and test–retest reliability [Mokkink et al., 2010].

Table 1. Mean, Standard Deviation and Range of Child and Parent Scores on Key Measures

Measure	Mean	SD	Range
CDI raw score	22.56	8.55	5–41
SSP hyper	76.66	18.64	33–115
SSP hypo	21.36	7.02	7–35
SCARED-P	29.1	16.35	0–65
SCARED-C	30.4	16.8	3–68
SDQ strengths	5.11	2.59	0–10
SDQ difficulties	19.98	6.55	4–35
ASC-ASD parent (P)	26.19	14.69	1–67
ASC-ASD child (C)	25.32	16.2	2–64
RBQ	23.11	12.07	1–53

SD, standard deviation.

Nonparametric analyses were conducted as anxiety scores were not normally distributed. As this was the first analysis conducted on the new item pool/adapted measure, exploratory factor analysis was chosen to examine its factor structure and content validity [Osborne, 2014]. A polychoric correlation matrix was chosen as it allowed factor analysis of data with a non-normal distribution and ordinal response option formats [Baglin, 2014; Garrido, Abad, & Ponsoda, 2013]. The analysis was run using FACTOR software (version 9) [http://psico.fcep.urv.es/utilitats/factor/; Lorenzo-Seva & Ferrando, 2006]. The method of rotation was oblique being more suited to psychological concepts (Direct Oblimin) [Costello & Jason, 2005; Osborne, 2014].

Results

A total of 573 families were contacted and 170 responded (34%) comprising data from 170 parents and 157 children. Mean child age was 11.1 (SD = 2.1) years; there were 121 male and 36 female child respondents. There were no significant differences between responders and nonresponders regarding gender, age, type of (DSM-IV) ASD diagnosis, age at diagnosis and anxiety reported as present or not by parents (data not shown). (Table 1).

Factor Analysis

Step 1. First the factor structure of the 37 original RCADS anxiety items (excluding the 10 depression items) was examined to determine whether the original six factor structure was replicated [Chorpita et al., 2000; Chorpita et al., 2005; Ebesutani et al., 2009]. To test the predicted number of factors plus and minus one we looked at a 4, 5, and 6 factor structure [Osbourne, 2014]. Examination of the factor structures extracted indicated that OCD items did not load in the expected way and rather than forming a distinct subscale the OCD items loaded in a complex way across several factors. The OCD items were therefore excluded from further analysis.

Step 2. The original RCADS items were then combined with items from the three new proposed subscales, resulting in 58 items in the parent and 57 in the child versions. The suitability of the data for a factor analysis was supported by a positive definite correlation matrix, a significant Bartlett's statistic ($P < .001$), and a very good sampling adequacy (KMO = 0.92). We hypothesised a seven factor model (the four original RCADS subscales plus uncertainty, sensory, and phobia) would best fit the remaining items and so initially tested for 6, 7, and 8 factors. Complex factor loadings at 6–8 factors suggested an over-factored model, and as the scree plot indicated a potential four factor model for both the parent and child versions, 3, 4, and 5 factor models were then examined. A cut point was then set so that items with factor loadings <.5 were excluded [Tabachnick & Fidell, 2013]. Setting the cut point at .5 meant none of the items in the parent and child versions was complex, that is, all were single loadings. The remaining 24 items loaded on four factors. The content of these four factors were considered and the following factors were identified, *Performance Anxiety* (5 items), *Anxious Arousal* (6 items), *Separation Anxiety* (5 items), and *Uncertainty* (8 items).

Factor analysis was then repeated on the remaining 24 items to verify the model for both versions. The final factor structure of the new questionnaire, the Anxiety Scale for Children – ASD (ASC-ASD), is shown in Tables 2 and 3. Three items were retained in the child version though the loading was <.5 to match the parent version (see Table 3).

Reliability

Internal consistency of the ASC-ASD total score and subscales was good to excellent, with Cronbach's alpha for the full scale parent .94 and child version .94; alpha for subscales on the parent ASC-ASD were: performance (.89), separation (.87), arousal (.87), and anticipatory (.91); and for the child version: performance (.85), separation (.85), arousal (.88), and anticipatory (.88).

One month test–retest reliability was excellent for the parent ($r = .84$) and child versions ($r = .82$); with intraclass correlations between the total score at Time 1 and Time 2 (parent ICC = .84; child ICC = .82); and parent/child agreement ($r = .68$) was high.

Validity

Convergent validity was demonstrated by significant correlations between ASC-ASD ratings and sensory processing hyper sensitivity: rs = −.71 ($P = .000$; parent; $n = 118$) and rs = −.44 ($P = .000$; child; $n = 109$); and

Table 2. Final Factor Structure of ASC-ASD-Parent

	Uncertainty	Separation	Arousal	Performance	
7. My child worries when he/she thinks he/she has done poorly at something in case people judge him/ her negatively	0.123	0.081	−0.065	0.742	Y(A)
13. My child feels scared when taking a test in case they make a mistake or don't understand the questions	0.120	0.106	−0.085	0.760	Y(A)
17. My child worries about being away from me	0.194	0.787	−0.007	−0.044	Y
22. My child worries about being in certain places because it might be too loud, or too bright or too busy	0.745	0.096	0.051	−0.036	N
23. My child worries about doing badly at school work	−0.119	0.017	0.043	0.899	Y
24. My child always wants to know what will happen next	0.640	0.058	−0.085	0.108	N
25. My child worries that something awful will happen to someone in the family	−0.023	0.721	0.055	0.153	Y
27. My child suddenly feels so anxious he/ she feels as if he/she can't breathe when there is no reason for this.	−0.049	0.257	0.725	0.028	Y(A)
28. My child is afraid of new things, or new people or new places	0.724	0.084	0.014	0.137	N
32. My child needs to always be prepared before things happen	0.805	0.031	−0.052	0.007	N
33. My child feels scared to be away from home because his/ her parents are familiar with his/ her bedtime routine	0.422	0.528	−0.025	−0.049	Y(A)
38. My child worries that people will bump into him/ her or touch him/ her in busy or crowded environments	0.641	−0.086	0.313	−0.041	N
49. My child suddenly starts to tremble or shake when there is no reason for this	0.072	−0.107	0.913	−0.109	Y
51. My child worries that something bad will happen to him/her	0.025	0.556	0.215	0.201	Y
53. When my child has a problem, he/she feels shaky	0.146	−0.063	0.736	0.080	Y
54. My child is afraid of entering a room full of people	0.782	−0.075	0.052	0.104	N
56. Feeling unsure stops my child from doing most things *(behavioural paralysis item to match child version)*	0.526	0.009	0.127	0.239	N
60. My child worries what other people think of him/her e.g. that he/ she is different	0.105	−0.059	0.103	0.698	Y(A)
61. My child is afraid of being in crowded places (like shopping centres, the movies, buses, busy play-grounds) in case he/ she is separated from his/ her family	0.559	0.308	0.126	0.018	Y(A)
65. My child suddenly becomes dizzy or faint when there is no reason for this	−0.006	0.046	0.838	0.033	Y
68. My child's heart suddenly starts to beat too quickly for no reason	−0.006	0.082	0.735	0.179	Y
70. My child worries that he/she will suddenly get a scared feeling when there is nothing to be afraid of	0.022	0.360	0.558	−0.023	Y
72. My child feels afraid that he/she will make a fool of him/herself in front of people	0.107	−0.107	0.041	0.730	Y
74. My child worries when in bed at night because he/ she does not like to be away from his her parents/ family	0.006	0.573	0.290	0.148	Y(A)

RCADS item (Y: yes; A: amended; N: new)

repetitive behaviours: rs = .58 (P = .000; parent; n = 128); rs = .41 (P = .000;child; n =115); and the SDQ emotional subscale (rs = .76; P = .000; parent n = 127) (rs =.56 P = .000; child n = 114). Similarly, there were significant correlations between the ASC-ASD and the SCARED (rs = .91, P = .000: parent versions, n = 124) and rs = .88 (P = .000; child versions; n = 114). Correlations between the SCARED and the ASC-ASD were stronger than between the ASC-ASD and the CDI-2 (rs = .65; P = .000; parent (n = 127); and rs = .44, P = .000; child (n = 114), and the ASC-ASD and the SDQ difficulties subscale (rs = .59 P = .000; parent (n = 125); rs = .44 P = .000; child (n = 112). This stronger correlation with the SCARED suggests the ASC-ASD is more specifically a measure of anxious affect, rather than a measure of mental health in general.

Table 3. Final Factor Structure of ASC-ASD-Child

	Separation	Uncertainty	Arousal	Performance	
4. I always need to be prepared before things happen	0.219	0.135	−0.111	0.301	N
10. I worry when I think I have done poorly at something	0.076	0.190	−0.039	0.660	Y
12. I am afraid of entering a room full of people	0.002	0.714	0.075	−0.025	N
18. I feel scared when I have to take a test in case I make a mistake	0.324	−0.078	0.057	0.626	Y(A)
21. I worry about being away from my parents	0.658	0.226	−0.029	0.163	Y
27.b I worry people will bump into me or touch me in busy or crowded environments	0.015	0.514	0.291	0.051	N
28. I worry that I will do badly at my school work	0.188	0.021	−0.066	0.763	Y
30. I worry that something awful will happen to someone in my family	0.264	0.098	0.076	0.484	Y
32. I suddenly feel as if I can't breathe when there is no reason for this	−0.010	−0.027	0.759	0.129	Y
33. When I don't know what will happen, I can't do things	0.024	0.507	0.167	0.221	N
36. I am afraid of new things, or new people or new places	0.008	0.888	−0.097	−0.003	N
48. I suddenly start to tremble or shake when there is no reason for this	−0.033	0.126	0.804	−0.050	Y
49. I worry that something bad will happen to me	0.076	0.330	0.058	0.417	Y
50. I worry what other people think of me	−0.211	0.031	0.154	0.807	N
52. I worry if I don't know what will happen e.g. if plans change	−0.061	0.528	0.217	0.231	N
55. When I have a problem I feel shaky	0.068	0.127	0.698	−0.034	Y
56. I am afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds) in case I am separated from my family	0.219	0.639	0.086	0.069	Y(A)
57. All of a sudden I feel really scared for no reason at all	0.139	−0.045	0.757	0.060	Y
59. I suddenly become dizzy or faint when there is no reason for this	0.011	0.038	0.819	−0.093	Y
63. My heart suddenly starts to beat too quickly for no reason	−0.010	−0.034	0.904	0.072	Y
67. I feel afraid that I will make a fool of myself in front of people	−0.180	0.181	0.128	0.588	Y
69. I worry when I go to bed at night because I don't like to be away from my parents/ family	0.551	0.008	0.320	0.225	Y(A)
70. I worry about being in places that are too loud, or too bright or too busy	0.058	0.761	0.043	0.026	N
71. I would feel scared if I had to stay away from home overnight because I like to be close to my parents/ family	0.639	0.250	0.252	−0.118	Y(A)
Alpha=.94					

RCADS item (Y: yes; A: amended; N: new)

Discussion

The aim of this study was the development and preliminary evaluation of an anxiety scale for use with children with ASD. The outcome was the production of the freely available Anxiety Scale for Children – ASD (ASC-ASD), parent and child versions. The ASC-ASD has a different content and factor structure from the original RCADS, with four subscales in both the parent and child versions: Performance Anxiety, Uncertainty, Anxious Arousal, and Separation Anxiety. Our initial evaluation of the psychometric properties of the new measures is promising, with good validity, reliability, and internal consistency. Correlations between the total scores of both child and parent versions of the ASC-ASD and our other measure of anxiety, the SCARED, were high. This provides evidence that the ASC-ASD is a valid measure of anxious affect. So, what does the new measure add? We propose that following the development process, the ASC-ASD includes anxiety-related items that are particularly appropriate to the specific phenomenology of anxiety in ASD. Our new measure comprises four subscales, in addition to the total score, reflecting this phenomenology. It is important to reflect on whether the presence of subscales matters. The formation of subscales has utility for treatment and

research, as they provide more detailed information about anxiety profiles than can be derived from a total score. In turn, this additional information can be utilised to guide formulation and treatment planning or hypothesis development. The unique subscales, and the relationship between the subscales and an overarching anxiety construct for ASD, may best be examined empirically in future studies by the use of bifactor models where each item is specified to load on both a specific factor and a general factor, where the specific factors are uncorrelated with each other and with the general factor [Reise, Moore, & Haviland, 2010]

In developing the ASC-ASD we incorporated items related to uncertainty, sensory issues and phobias. Results indicated the presence of uncertainty related anxiety that incorporated a number of sensory items. This supports the well-established association between sensory hypersensitivity and anxiety in ASD [Ben-Sasson et al., 2008; Green & Ben-Sasson, 2010; Lidstone, Uljarevic et al., 2014; Reynolds & Lane, 2009; Wigham et al., 2015] and the emerging evidence of the important role that intolerance of uncertainty may have in anxiety in ASD [Boulter et al., 2014; Chamberlain et al., 2013; Wigham et al., 2015).

Our factor analysis has yielded further interesting findings in relation to the phenomenology of anxiety in ASD. Of note, we were unable to replicate an OCD factor in our analysis of the original RCADS items in either the parent or the child versions. We also found no indication of a GAD factor in our sample. Further, the social phobia items with strong factor loadings related specifically to performance-related anxiety rather than broader social evaluation issues, perhaps reflecting concerns individuals with ASD experience in relation to rule violation and making mistakes irrespective of the fear of negative evaluation by others inherent in social phobia. Previous research which has used measures developed and validated with typically developing children in ASD samples includes considerable variability in the rates of OCD, GAD, and social phobia in ASD, perhaps reflecting underlying issues with conceptualisation and measurement.

We found no evidence of a specific phobia factor in our sample, despite high rates consistently reported in other studies [de Bruin et al., 2007; Leyfer et al., 2006; Sukhodolsky et al., 2008]. Mukaddes and Fateh [2010] reported that there is little overlap in the content of phobias in children with ASD compared with typically developing children, which may explain the lack of a coherent factor in relation to these experiences. They also suggest that for young people with ASD, phobias were frequently associated with loud noises [Gjevik et al., 2011; Leyfer et al., 2006; Mukaddes & Fateh, 2010], and crowded places [Leyfer et al., 2006; Russell & Sofronoff, 2005] and it was hypothesised that this may be a result of heightened sensory sensitivity; as such these phenomena are likely to have been captured by items incorporated into our uncertainty scale.

We did find evidence for separation concerns in our sample with an identified factor which is consistent with the original separation anxiety subscale of the RCADS. The central feature of separation anxiety is "excessive anxiety concerning separation from home or from those to whom the individual is attached" [American Psychiatric Association, 2013; p.76]. Features of ASD including resistance to change in routine and new settings [Gjevik et al., 2011], can mimic symptoms of separation anxiety. This has led authors to suggest that anxiety displayed in these circumstances is not necessarily attachment-related but may be more related to core features of ASD [Leyfer et al., 2006]. However, the items that comprise the separation subscale in the ASC-ASD do appear to relate specifically to separation from and concerns relating to caregivers, indicating that a form of separation anxiety, perhaps related to the parent's role in mediating the child's interaction with the world, is a real phenomenon in ASD.

Regarding limitations, our study only included children with ASD with average ability. We, therefore, do not yet know whether the ASC-ASD would be appropriate for use with children with ASD and intellectual/learning disability and intend to investigate this in the future. Nor do we know whether the measure would be as effective in measuring the anxiety of adults with ASD, though we do know that anxiety is a pressing issue throughout life for those with the condition, highlighting the need for the development of anxiety assessments suitable for use across the lifespan. It is possible that we may have experienced recruitment bias with parents more likely to consent if their children were troubled by anxiety. However, we found no systematic differences between the responders and nonresponders on a variety of demographic variables. Our sample size for a factor analytic study is modest but the application of stringent criteria, and the similarity of factor solutions in both parent and child samples, suggest a degree of robustness. New and larger samples will ultimately confirm or not the stability and robustness of the solution.

Regarding future research, anxiety levels in ASD have been linked to developmental ability, with higher anxiety associated with higher ability [Salazar et al., 2015; Sukhodolsky, 2008]. This may be a measurement artefact, reflecting the lack of a valid measure of anxiety for children with ASD and intellectual disability, but future research is required to evaluate this further [Hallett, Lecavalier et al., 2013a; Hallett, Ronald et al., 2013b]. The RCADS item scoring system has been retained in our study; however although the ASC-ASD is derived from the RCADS it would not be appropriate to utilise

RCADS norm scores and cut points with the ASC-ASD. The ASC-ASD is a dimensional/phenomenological measure of anxiety developed specifically to include the manifestations of anxiety found among children with ASD, rather than a measure based on DSM nosology that may be used to make categorical decisions about anxiety disorder. Future work with larger samples would be helpful to establish indicative clinical cut-offs to aid the interpretation of profiles.

Our goal at the outset was to begin the work of devising a measure of anxiety specifically for use with young people with ASD. The outcome of this endeavour is the development of the ASC-ASD. Our freely available new measure developed in collaboration with children and parents shows promise in terms of its measurement properties, however, further validation and or modification of the measure is needed and we welcome the use of the tool by other groups of clinicians and researchers.

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