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ORIGINAL PAPER

The Interoception Sensory Questionnaire (ISQ): A Scale to Measure Interoceptive Challenges in Adults

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Abstract
Increasing attention is being paid to how adults on the autism spectrum perceive and interpret the interoceptive sense. This 20-item Interoception Sensory Questionnaire represents a single factor scale that can be interpreted as representing confusion about interoceptive bodily states unless these states are extreme (Alexisomia), and has been designed to discriminate across populations (total sample 511 participants). Findings showed that 74% of adults with autism reported interoceptive confusion. Another finding of the study was that as autistic traits increased, interoceptive confusion increased, with adults with diagnosed autism scoring highest on the construct. Implications for physiological self-regulation as well as physical health outcomes are discussed, as well as recommendations for future research.

Keywords Autism · Asperger's syndrome · Interoception · Alexisomia · Hunger · Thirst · Pain · Temperature · Sensory perception

Introduction

Sensory processing difficulties and challenges are experienced by many with Autism Spectrum Disorder (ASD), with an estimated 45–96% experiencing difficulties with regulating sensation and perception (Schaaf and Lane 2015). Primarily, research has focused on external stimuli processing, however a recent review has found that many on the spectrum also face difficulties with internal stimuli processing (DuBois et al. 2016). Internal sensations and perceptions form part of the interoceptive sense, which includes the sensations of pain, temperature, hunger, satiety, muscle tension, taste, heartbeat perception, thirst, itch, air hunger, and affective touch (slow gentle stroking on hairy skin).

According to the Salience Network model (SN) of interoception, the network's function is to identify what is most relevant among several stimuli in order to guide behaviour (Uddin and Menon 2009). Research on the SN model has shown that the insular cortex (IC) and the anterior cingulate cortex (ACC) act as a site of integration between internally and externally relevant stimuli in order to ascertain what are the most salient stimuli to respond to (Chang 2013; Craig 2002; Menon and Uddin 2010). The authors of the model suggest that interoceptive signals that report the moment-to-moment condition of the body play an important role in this detection of salient stimuli.

The clinical importance of understanding interoceptive processing in those with ASD is increasingly being acknowledged and it is now understood that inaccuracies with sensing hunger, thirst, heat, cold, or pain may account for some of the clinically-relevant behaviours associated with ASD (Mahler 2016). For example, it is known that many people with ASD have unusual eating and drinking behaviours (Keen 2008; Postorino et al. 2015; Zobel-Lachiusa et al. 2015), with noted feeding problems including food refusal, long mealtimes, short intervals between meals, and failure to thrive (Barnevik Olsson et al. 2013). These challenges underpin broader health difficulties and highlight the complex link between psychophysiological processes commonly seen in people with autism and health outcomes.

People with ASD have unusual pain related behaviours and autonomic responses (Dubois et al. 2010), unusual

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voiding (bladder and bowel) behaviours (von Gontard et al. 2015), thermoregulatory and autonomic instability (Dhossche and Wachtel 2010), and unusual thermoregulatory sensitivity (Cascio et al. 2008; Duerden et al. 2013). Small scale qualitative studies have observed unusual perceptions of internal stimuli in adults with autism. For example, "I rarely feel any hunger or thirst. I have learned to recognize the signals from my body, when I get distinct examples—like when I have been without food, for too long, I feel sick and dizzy" (Elwin et al. 2012, p. 425). There is currently a small but growing body of evidence to suggest that many individuals with autism have challenges with accurately sensing the body's physiological state (Elwin et al. 2016; Fiene and Brownlow 2015; Quattrocki and Friston 2014; Uddin and Menon 2009), but inconsistent approaches and varying outcome measures characterise the existing research. There is also evidence that many individuals with autism have challenges with physiological self-regulation. For example, when investigating fluid drinking behaviours in adults with autism, Terai et al. (1999) found that excessive water drinking behaviour occurs more often in adults with autism and concluded that this is due to a factor intrinsic to autism itself, separate from intellectual disability or psychotropic medication.

In a recent study by Mills and Wing (2015), it was found that 474 out of 634 respondents (74%) reported severe excessive fluid drinking behaviours that had mostly begun before the age of 5 years. The potential for severe health consequences from excessive fluid drinking underscores the clinical importance of this issue. Whilst the authors of the study did not also examine whether hypodipsia exists in some individuals, the study does highlight the struggles with physiological self-regulation that occur in many individuals with autism. Additionally, Fiene and Brownlow (2015) found a positive relationship between self-reported body awareness and amount of fluids consumed per day in neurotypical adults, but not in adults with autism. Specifically, autistic adults were just as likely to consume large amounts of non-alcoholic fluid (over 20 glasses per day) if they reported lower awareness or very low amounts of fluid (1–3 glasses per day) if they reported higher awareness. The finding of no relationship between reported awareness and drinking behaviours in autistic adults suggests that the amount a person consumes is not related to perceptions of internal bodily signals but may be more of a cognitive process. This is an important finding, and has implications for physiological self-regulation as well as physical health outcomes. Limitations of this study were that the measure of body awareness used was validated on neurotypical populations and so its validity in capturing dominant autistic experiences of interoception is unknown. Also, it only examined thirst, hunger, temperature, satiety and the prediction of onset of illness, not all domains of interoception. Therefore, the Interoception Sensory Questionnaire (ISQ) was designed by the authors to capture variance in interoception specifically relevant to the difficulties faced by adults with autism.

The Current Study

Based on the salience model of interoception (Uddin and Menon 2009; Uddin 2015), qualitative analyses of online vlogs and semi-structured interviews with adults on the autism spectrum (Fiene 2018), it was anticipated that the current research question could be answered: *What common and dominant perceptions of interoception discriminate between autistic and non-autistic experiences?* The phenomenon of interest was impaired interoception in adults, with the aim of the study to develop a self-report measure that would capture variance in interoception difficulties specific to the experience of people with autism. Another aim was to ensure scale items were in a language that was natural to adults with autism, capturing autistic language and expression (Chahboun et al. 2016). The final aim was to conduct preliminary assessment of the scale's structural validity, internal consistency, convergent and discriminant validity. As this scale's development was exploratory in nature, no predictions were made with regard to the structural validity or internal consistency, however predictions about convergent and discriminant validity are stated in the following section.

Prediction of Correlations Between ISQ and Scales of Related Constructs

Assuming the validity of the instruments used, and the working definition theory of interoception outlined above, the following pattern of correlations was hypothesised. Firstly, it was predicted that a moderate to strong positive correlation would be found between the refined ISQ and the Toronto Alexithymia Scale (TAS-20; Taylor et al. 1992), as challenges with identifying and describing interoceptive bodily states is a construct expected to overlap with challenges with identifying and describing emotions in the self.

It was also predicted that ISQ scores would demonstrate (a) a small to moderate negative correlations with the openness and conscientiousness sub-scales of the BFI, as these have theoretically been proposed to be associated with good interoceptive awareness (Ferentzi et al. 2017) and (b) a small to moderate positive correlation with the neuroticism subscale of the BFI, as emotional stability has also theoretically been proposed to be associated with good interoceptive awareness (Kanbara and Fukunaga 2016). No other predictions with regard to the other sub-scales of the BFI were made as there is yet no theoretical framework that provides

links between these sub-scales and interoceptive awareness. It was also predicted that there would be small to moderate negative correlations with the attention regulation, emotional awareness, self-regulation and body-listening sub-scales of the mindfulness-based multidimensional assessment of interoceptive awareness (MAIA; Mehling et al. 2012). It was also predicted that discriminant validity would be established through a non-significant correlation with gender and years of education, as interoception involves innate physiological processes that have been evolutionarily programmed to regulate physiological needs (Cameron 2002). As such, it was predicted that gender and years of education would not be correlated with these innate processes.

Method

Participants

The neurotypical sample consisting of 459 participants and the autism sample consisted of 52 participants. Participants in the autism group were required to have been previously diagnosed with autism by a suitably qualified professional (Paediatrician, Psychiatrist or Clinical Psychologist). As the total sample consisted of 511 participants and there were 60 items in the draft ISQ, this exceeded a minimum recommended number of five respondents per item for exploratory factor analysis (Gorsuch 1983; Hatcher 1994). Table 1 lists the characteristics of survey participants.

Design and Measures

A cross-sectional online survey design was used to address the study aims. Convenience sampling was utilised for two populations. Autistic and non-autistic participants responded to a number of self-report measures online, including the new 60-item pool developed for the new ISQ. Demographic data including age, gender, years of education, autism diagnosis and age at diagnosis were collected.

ISQ

The initial strategy for item development of the ISQ was to base the items on the common and dominant manifestations of impaired interoception in adults with autism, based on the salience model and the findings from qualitative analyses of online vlogs and semi-structured interviews with adults on the autism spectrum (Fiene 2018). These common and dominant manifestations included: (a) difficulty identifying and describing interoceptive bodily signals unless extreme, (b) hypo-reactive and hyper-reactive perception, (c) affective touch allodynia, (d) external cue reliance, (e) reduced affective/motivational components to act upon bodily states. As adults with autism tend to use more literal rather than figurative language (Chahboun et al. 2016), the aim was for the wording of the items to be as specific as possible to aid clarity, and to also generate many items to identify a wide variety of ways that impaired interoception can be stated by adults on the spectrum. As such, the 60-item pool encompassed these five manifestations of impaired interoception. Participants responded to ISQ items on a seven-point numerical response scale ranging from 1 ("not at all true of me") through to 7 ("very true of me"). Three items were reverse scored, (e.g., "I am aware of my body and the sensations that I feel such as hunger, thirst and heartbeat"). Items were scored such that higher scores represented increased interoceptive challenges. As this is a new scale being developed and introduced in this paper, details surrounding scale refinement, reliability, convergent and divergent validity analyses will be outlined and discussed at length in later sections.

Table 1 Sample characteristics (N = 511)

Variable	Autism ($n = 52$)	Neurotypical ($n = 459$)
Males (n, %)	23 (44.2)	173 (37.7)
Females (n, %)	27 (51.9)	286 (62.3)
Gender unspecified (n, %)	2 (3.8)	n/a
Age (years, *M*/*SD*)	34.54 (11.26)	33.49 (10.29)
Age at autism diagnosis (years, *M*/*SD*)	24.71 (15.01)	n/a
Years of education (*M*/*SD*)	15.40 (4.18)	15.12 (2.51)
Survey source		
Undergraduate students (n, %)	4 (7.7)	159 (34.7)
MTurk (n, %)	17 (32.7)	281 (61.2)
Community members (n, %)	31 (59.6)	19 (4.1)

MTurk Amazon's Mechanical Turk

Toronto Alexithymia Scale (TAS-20)

The 20-item TAS-20 (Taylor et al. 1992) was developed to measure the personality construct of Alexithymia according to the three factor model, which includes: (a) difficulty identifying emotions in the self; (b) difficulty describing emotions to others, and (c) an externally oriented thinking style. The scale demonstrates good internal reliability ($a = 0.80$) and construct validity (Parker et al. 1993), as well as adequate convergent and divergent validity (Bagby et al. 2014).

The TAS-20 includes items such as "I often don't know why I'm angry", with responses to ranging on a five point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*). Items for each subscale are summed to produce three overall scores, with higher scores on each representing increased difficulties with identifying and describing feelings and possessing a more externally-oriented thinking style.

Big Five Inventory (BFI)

The BFI is a 44-item inventory that measures an individual on the Big Five Factors (dimensions) of personality: extraversion vs. introversion; agreeableness vs. antagonism; conscientiousness vs. lack of direction; neuroticism vs. emotional stability; openness vs. closedness to experience (John et al. 1991). The reliability and validity of the BFI has been examined across age, gender and cultures, with internal reliability ranging from 0.78 to 0.87, showing that the BFI is a reliable scale (Arterberry et al. 2014). Participants are asked to self-report how they see themselves on items such as "is talkative" and "can be moody" on a five-point Likert scale, from one (*disagree strongly*) to five (*agree strongly*). Items for each subscale are summed to produce five overall factor scores, with higher scores on each representing a tendency to be more extraverted, agreeable, conscientious, neurotic or open to new experiences.

Autism Spectrum Quotient-10 items (AQ-10)

The AQ-10 is a 10-item short version of the Autism Spectrum Quotient for Adults (AQ), which measures autistic traits and was designed as a tool for professionals to use to aid decisions about on-referral of adults for full diagnostic assessment for autism (Allison et al. 2012). At the cut-off point of six on the total scale score, the AQ-10 has shown sensitivity of 0.88 and specificity of 0.91, with internal consistency of above 0.85 on a sample of 449 adults with autism and 838 neurotypical adults (Allison et al. 2012). Items such as "I often notice small sounds when others do not" and "I know how to tell if someone listening to me is getting bored" are asked on a four-point Likert scale ranging from "definitely agree" to "definitely disagree". Items 1, 7, 8, and 10 are scored as 1 point for definitely or slightly agree, and items 2, 3, 4, 5, 6 and 9 are scored as 1 point for definitely or slightly disagree. All other responses are scored as 0. Items are then summed, with higher scores indicating greater levels of autistic traits.

Multidimensional Assessment of Interoceptive Awareness (MAIA)

The 32-item MAIA (Mehling et al. 2012) is a self-report mindfulness measure on interoceptive awareness, designed for experimental interoception research and for assessment of the effectiveness of mind–body integration training. Focus groups on item development included leading instructors in mindfulness meditation, yoga, Tai Chi, Feldenkrais, Alexander technique, breath therapy and Somatic Experiencing (Mehling et al. 2012), as well as students of these training programmes. Sample participants for scale development were also sourced from these groups as well as students of these therapies.

For the current study, four of the eight sub-scales of the MAIA were used: attention regulation, emotional awareness, self-regulation and body listening, consisting of 19 items in total. Items such as "I listen to my body to inform me about what to do" and "I am able to consciously focus on my body as a whole" were asked on a six-point numerical response scale, ranging from 0 (*never*) to 5 (*always*). Items for each subscale are summed to produce four overall scores, with higher scores representing increased interoceptive awareness. Reliability analyses of the four sub-scales used in this study show good internal consistency: attention regulation: $\alpha = 0.87$; emotional awareness: $\alpha = 0.82$; self-regulation; $\alpha = 0.83$; body listening: $\alpha = 0.82$. Construct validity showed that the MAIA is able to maximally distinguish between experienced teachers of mindfulness-based integration training programmes and students of such programmes.

Procedure

Ethical approval for this study was received from the university's Human Research Ethics Committee (H16REA145), and participants provided online informed consent prior to survey completion. The study was conducted as an online survey for all participants. The neurotypical participants comprised approximately 35% undergraduate psychology students who were offered a 1% course credit for participation and community members, sourced from a link placed on social media (with no incentive offered). Additional recruitment was via Amazon's Mechanical Turk (MTurk), where participants were offered an AUD$3.00 incentive for participation. Use of MTurk has become increasingly popular in behavioural research, and guidelines have been provided for its use when conducting online studies (Mason and Suri 2012). It has also been found that MTurk

participants are more demographically diverse than typical university samples, with test–retest reliabilities being very high ($r = .80–.94$; mean $r = .88$) and more favourable than traditional methods (Buhrmester et al. 2011).

Individuals with autism were recruited via links advertised on various autism specific websites, in addition to some being recruited via the means above. As some respondents from both the student and MTurk groups had previously been diagnosed with autism, these were included in the autism sample in all analyses. Participants were advised that the survey would take approximately 30–35 min of their time. Participation was entirely voluntary, with respondents being able to withdraw at any time.

Statistical Analyses

Before scale refinement was undertaken, it was important to ascertain whether participant source (i.e., MTurk and student participants) produced differences in survey responses. Independent samples *t*-tests were undertaken to compare mean responses and effect sizes for participants from MTurk and student sources on all scales. See results in Table 2. No statistically significant differences were found between MTurk and student responses on the 60-item ISQ, the TAS-20, the agreeableness and openness sub-scales of the BFI and the attention regulation, self-regulation and body listening sub-scales of the MAIA. Student respondents scored higher on the extraversion and neuroticism sub-scales of the BFI, as well as the Emotional awareness sub-scale of the MAIA, and these were small to moderate effects. Student respondents scored lower on the conscientiousness sub-scale of the BFI as well as the AQ-10, and these were small to moderate effects. As most of the comparisons showed either no-difference or small-differences, it was deemed acceptable to pool the samples.

Results

Factorability of Items

To explore the underlying structure and factorability of the 60-item ISQ pool, principal component analysis (PCA) was conducted. The inter-item correlation matrix revealed no multi-collinearity or singularity (determinant > 0.000001), with small to moderate correlations found. Kaiser–Meyer–Olkin (KMO) was 0.95, indicating a good probability of (PCA) yielding distinct and reliable factors (Field 2009). The scree plot and the proportion of variance explained (requiring > 50%) informed the number of components, which initially suggested a one component solution.

Table 2 Means and standard deviations of Scale Scores for undergraduate students and MTurk respondents

	ISQ	TAS	BFI						MAIA			
			Extraversion	Agree	Concsc	Neurot	Open	AQ-10	Attention regulation	Emotional awareness	Self-regulation	Body listening
Student (*M*/*SD*)	166.02 (48.16)	46.91 (12.79)	24.69 (7.31)	33.19 (6.13)	31.64 (6.07)	25.05 (6.35)	34.68 (6.37)	2.82 (1.80)	20.07 (7.10)	17.77 (5.47)	11.89 (4.26)	8.12 (3.81)
Mturk (*M*/*SD*)	171.87 (61.14)	48.00 (13.81)	22.97 (7.56)	33.12 (6.63)	34.29 (6.56)	22.22 (7.52)	35.95 (6.96)	3.47 (1.93)	20.53 (8.05)	16.22 (5.60)	11.47 (4.84)	8.04 (4.14)
Effect Size (Cohens *d*)	−0.11	−0.08	**0.23**	0.01	**−0.42**	**0.41**	−0.19	**−0.23**	−0.06	**0.28**	0.09	0.02

MTurk Amazon's Mechanical Turk respondents

Bold small but significant effect sizes

ISQ Interoception Sensory Questionnaire-60 items, *TAS-20* Toronto Alexithymia Scale, *BFI* Big Five Inventory: extraversion vs. introversion, agreeableness vs. antagonism, conscientiousness vs. lack of direction, neuroticism vs. emotional stability, openness vs. closedness to experience; *AQ-10* Adult Autism Spectrum Quotient-10 items; *MAIA* multidimensional assessment of interoceptive awareness

Item Analysis

Given the purpose of the scale was to capture variance in interoception with particular relevance to interoception difficulties experienced by adults with autism, items were assessed on their ability to discriminate between individuals in our sample that were diagnosed with autism and neurotypicals. This analysis aimed to determine whether items were sensitive to variation in interoception difficulties known to exist between adults with and without autism. This analysis does not attempt to make inferences about population differences but rather to interrogate the capacity of the items to detect known population differences. Therefore, this analysis is concerned with the magnitude of mean differences and not statistical significance.

In addition to comparing participants that self-reported a diagnosis of ASD with participants that reported never receiving such a diagnosis, complimentary analyses were also conducted using the AQ-10. These were done because of the unreliability of formal diagnosis (and the current study's reliance on participant self-reporting of such diagnosis), and secondly, because of the large uneven sample sizes produced when we rely solely on the presence of a formal diagnosis to determine group membership. To address these issues, two new grouping variables were created. Firstly, responses were split at the 33rd and 66th percentile to create low, middle, and high scoring groups. The low and high scoring groups were used to examine the extent that interoception items could discriminate between groups scoring high and low on autistic traits (this analysis has the advantage of more evenly sized samples). The final grouping variable was based on the AQ-10 recommended cut-off score of six, which the authors recommend as a threshold for warranting referral for specialist diagnostic assessment.

SPSS GLM analysis was used to calculate effect sizes representing the magnitude of mean difference in responses for all interoception items according to three independent (grouping) variables: (a) autism vs. neurotypical; (b) AQ-10 high 33 vs. low 33% and (c) AQ-10 threshold cut-off (6 or above vs. below 6). Partial eta squared was the statistic used to compare the performance of individual items. Items were removed if they failed to produce at least a medium effect size ($\eta^2 \leq 0.06$; Cohen 1988) for differences on at least two of the three grouping indicators. The results are displayed in Table 3. A total of 30 items met this criterion and were retained for further analysis. The item that discriminated strongest was "I have difficulty making sense of my body's signals unless they are very strong". The item that discriminated weakest was "I notice when I'm in pain straight away, and it's very intense". Importantly, the effect sizes derived from the complimentary analyses using the new AQ-10 grouping variables were very strongly correlated ($rs = .88–.89$) with those derived from using the formal diagnosis. This confirms that the comparison based on self-reported formal diagnosis was not unduly effected by largely uneven group sizes.

Exploratory Factor Analysis and Internal Consistency of the ISQ

The remaining 30-item pool was submitted to further exploratory factor analysis using principle axis factoring (PAF) and an oblique rotation (direct oblimin). The oblique rotation was selected because any resulting factors were expected theoretically to covary due to them representing related aspects of the interoception experience.

Kaiser's criterion (eigenvalue > 1.00), the scree plot, and the threshold for adequate proportion of variance explained (51.19%), converged in suggesting a one factor solution. An iterative process to scale refinement was followed with items that produced low communalities (< 0.35) or cross-factor loadings (> 0.32 on a secondary factor) deleted. Tabachnick and Fidell (2006) cite 0.32 as a good 'rule of thumb' for establishing cross-loading of items since it equates to approximately 10% of variance overlapping between item and factor. Items were also deleted if they did not have a high factor loading (using the stringent cut-offs suggested by Tabachnick and Fidell 2006). According to their criteria, item loadings > 0.63 are considered "very good" and represent almost 40% of overlap in variance between item and factor. Items 1, 4, 12, 23, 32, 37, 49, 51, 52 and 60 were removed based on this criterion. Following item refinement, PAF was re-extracted and the final solution contained a single factor that explained 57.33% of item variance from 20 items with strong loadings. Based on the highest loading items, this factor can be interpreted as representing confusion about interoceptive bodily states unless those states are extreme. Items reference (a) identifying and describing bodily states; (b) feeling the affective/motivational components to act upon bodily states, (c) externally cued physiological self-regulation. The final 20-item instrument with factor loadings is displayed in Table 4.

Internal consistency estimates were calculated using Cronbach's coefficient alpha, with > 0.70 considered adequate (Tavakol and Dennick 2011). As Cronbach's coefficient alpha was 0.96 for the single factor ISQ, this was considered excellent for the refined 20 item pool.

Descriptive and Comparison Statistics for the Current Sample

Using separate independent samples *t* tests, significant and very large differences were found in ISQ scores between the autism and neurotypical groups $t(509) = 11.97$, $M_{diff} = 41.54$, 95% CI [34.72, 48.36], $p < .001$, $d = 1.63$] as well as high vs. low autistic traits groups $t(340) = 10.15$, $M_{diff} = 26.06$, 95% CI

Table 3 Item discrimination analysis-60-item ISQ

Item #	Item stem	Autism/neuro-typical partial η^2	AQ-10 binned—top 33% vs. bottom 33%. partial η^2	AQ10 threshold of ≥ 6 partial η^2
ISQ01	I don't notice distinct feelings in my body when I know I should be thirsty	0.055	0.105	0.052
ISQ02	I seem to feel cold a lot more than everybody else	0.026	0.027	0.011
ISQ03	I experience pain from minor cuts as a very intense experience	0.017	0.030	0.015
ISQ04	I notice that slow gentle stroking on my forearm makes me feel uncomfortable as it is very intense	0.158	0.103	0.049
ISQ05	I have difficulty making sense of my body's signals unless they are very strong	0.204	0.196	0.107
ISQ06	I tend to rely on visual reminders (e.g. times on the clock) to help me know when to eat and drink	0.093	0.109	0.048
ISQ07	Even when I know that I am physically uncomfortable, I do not act to change my situation	0.126	0.097	0.047
ISQ08	I'm not sure how my body feels when it's a hot day	0.166	0.162	0.096
ISQ09	I'm not particularly sensitive to physical pain	0.037	0.013	0.004
ISQ10	I find it difficult to describe feelings like hunger, thirst, hot or cold	0.135	0.182	0.110
ISQ11	I don't feel bodily discomfort if I miss a meal	0.034	0.018	0.022
ISQ12	I have difficulty knowing when I've over-exerted myself when exercising	0.092	0.100	0.040
ISQ13	I experience even small bodily signals intensely and with urgency	0.053	0.044	0.013
ISQ14	I eat to a routine rather than any feeling of hunger	0.021	0.018	0.011
ISQ15	Sometimes I don't know how to interpret sensations I feel within my body	0.130	0.143	0.071
ISQ16r[b]	I feel in tune with the internal sensations of my body	0.037	0.124	0.072
ISQ17	My hunger appetite isn't as much of a priority as it seems to be for a lot of other people	0.045	0.038	0.030
ISQ18	If I have eaten too much, I often don't notice it until well afterwards	0.049	0.066	0.019
ISQ19	When someone strokes my arm, I don't tend to feel any emotion	0.028	0.017	0.012
ISQ20	I struggle to keep myself warm in the cool weather	0.016	0.011	0.001
ISQ21	Even when I know that I am hungry, thirsty, in pain, hot or cold, I don't feel the need to do anything about it	0.121	0.114	0.060
ISQ22	I struggle to keep myself cool in the hot weather	0.028	0.030	0.005
ISQ23	Eating is dictated mostly by the time on the clock rather than me feeling bodily urges to eat	0.049	0.066	0.030
ISQ24	I am never aware of my heart beat	0.002	0.005	0.001
ISQ25	If I injure myself badly, even though I can feel it, I don't feel the need to do much about it	0.079	0.073	0.038
ISQ26	I tend to crave very spicy foods	0.006	0.000	0.000
ISQ27	By the time I feel hungry I need to eat immediately	0.038	0.022	0.004
ISQ28	I notice that I feel pain more than other people	0.047	0.051	0.019
ISQ29r[b]	I am aware of my body and the sensations that I feel such as hunger, thirst and heartbeat	0.024	0.048	0.035
ISQ30	I tend to wear clothing based on the weather forecast rather than feeling hot or cold	0.013	0.030	0.007
ISQ31	I don't really experience a feeling of fullness after eating	0.030	0.055	0.021
ISQ32	I'm not able to pinpoint what it actually feels like when I'm blushing	0.088	0.062	0.045
ISQ33	Sometimes I act impulsively in response to my internal bodily signals	0.069	0.045	0.021
ISQ34	I only notice I need to eat when I'm in pain or feeling nauseous or weak	0.112	0.090	0.068
ISQ35	There are times when I am only aware of changes in my body because of the reactions of other people	0.154	0.142	0.073
ISQ36	I find it difficult to read the signs and signals within my own body (e.g. when I have hurt myself or I need to rest)	0.138	0.172	0.079

Table 3 (continued)

Item #	Item stem	Autism/neurotypical partial η^2	AQ-10 binned—top 33% vs. bottom 33%. partial η^2	AQ10 threshold of ≥ 6 partial η^2
ISQ37	Skin to skin contact with other people is something I try to avoid	0.050	0.131	0.055
ISQ38	When I injure myself quite badly, the pain doesn't bother me much	0.034	0.043	0.016
ISQ39	I have difficulty understanding when I am hungry or thirsty	0.133	0.146	0.086
ISQ40	I find it difficult to identify some of the signals that my body is telling me (e.g. if I'm about to faint or I've over exerted myself)	0.138	0.158	0.083
ISQ41	It is difficult for me to describe what it feels to be hungry, thirsty, hot or cold or in pain	0.124	0.138	0.078
ISQ42	I'll tend to keep a jumper on all day, even if the temperature gets hotter	0.049	0.048	0.030
ISQ43r[b]	I can detect when my heart is beating quicker than usual	0.004	0.035	0.016
ISQ44	I am confused about my bodily sensations	0.116	0.133	0.072
ISQ45	I notice that if I'm in an environment that is too warm, I can become distressed very quickly	0.042	0.063	0.026
ISQ46	I have difficulty locating injury in my body	0.113	0.147	0.052
ISQ47	I notice when I'm in pain straight away, and it's very intense	0	0.005[a]	0
ISQ48	I have difficulty feeling my bodily need for food	0.156	0.168	0.106
ISQ49	Sometimes I feel overwhelmed by signals that my body is sending me	0.142	0.120	0.083
ISQ50	My hunger is very easily ignored	0.031	0.031	0.026
ISQ51	Slight brushes against my skin causes a horrible tingly sensation	0.103	0.171	0.086
ISQ52	I don't usually notice thirst	0.070	0.121	0.070
ISQ53	Sometimes when my body signals a problem, I have difficulty working out what the problem might be	0.174	0.211	0.100
ISQ54	I have trouble keeping myself warm if it's a cold day	0.032	0.021	0.003
ISQ55	I don't tend to notice feelings in my body until they're very intense	0.106	0.119	0.064
ISQ56	I tend to get cold quickly and notice that I seem to wear more clothing than other people	0.022	0.024	0.007
ISQ57	Sometimes I have an internal sensation that I need to react to urgently	0.077	0.058	0.033
ISQ58	I tend to crave very plain foods	0.026	0.046	0.042
ISQ59	I find it difficult to put my internal bodily sensations into words	0.149	0.153	0.098
ISQ60	Even when I exercise I don't tend to feel my heart beating	0.056	0.099	0.039

All effect directions are positive (ASD group and high autistic traits groups scored higher), except for item marked

[a]Negative effect direction

[b]Reverse scored items

[21.01, 31.11], $p < .001$, $d = 1.07$]. This is expected given the items were selected for their ability to discriminate between these groups. The results of these independent samples *t* test are displayed in Table 5.

Initial results show that 74% of adults with autism had a total ISQ score greater than one standard deviation above the neurotypical mean (≥ 71 on the ISQ) and 46% had a total ISQ score greater than two standard deviations above the neurotypical mean (≥ 94 on ISQ). See Table 6 for overview of results for all groups.

Scale Validity Analyses

Convergent Validity

To assess convergent validity, a correlation analysis was conducted between the ISQ, the TAS-20, the sub-scales of the BFI and the four sub-scales of the MAIA. Table 6 presents the results of the correlation analysis. Nine out of 10 validity scales correlated significantly with ISQ scores. In addition, six of the seven predicted correlations confirmed the

Table 4 Principal axis factor loadings for 20 ISQ items

Number	Item stem	Factor loading
5	I have difficulty making sense of my body's signals unless they are very strong	0.802
6	I tend to rely on visual reminders (e.g. times on the clock) to help me know when to eat and drink	0.649
48	I have difficulty feeling my bodily need for food	0.787
8	I'm not sure how my body feels when it's a hot day	0.707
10	I find it difficult to describe feelings like hunger, thirst, hot or cold	0.712
15	Sometimes I don't know how to interpret sensations I feel within my body	0.762
25	If I injure myself badly, even though I can feel it, I don't feel the need to do much about it	0.644
34	I only notice I need to eat when I'm in pain or feeling nauseous or weak	0.648
35	There are times when I am only aware of changes in my body because of the reactions of other people	0.743
36	I find it difficult to read the signs and signals within my own body (e.g. when I have hurt myself or I need to rest)	0.802
39	I have difficulty understanding when I am hungry or thirsty	0.805
40	I find it difficult to identify some of the signals that my body is telling me (e.g. If I'm about to faint or I've over exerted myself)	0.818
41	It is difficult for me to describe what it feels like to be hungry, thirsty, hot, cold or in pain	0.804
44	I am confused about my bodily sensations	0.841
46	I have difficulty locating injury in my body	0.724
53	Sometimes, when my body signals a problem, I have difficulty working out what the problem might be	0.834
55	I don't tend to notice feelings in my body until they're very intense	0.780
59	I find it difficult to put my internal bodily sensations into words	0.816
21	Even when I know that I am hungry, thirsty, in pain, hot or cold, I don't feel the need to do anything about it	0.739
7	Even when I know that I am physically uncomfortable, I do not act to change my situation	0.672

ISQ Interoception Sensory Questionnaire-20 items

Table 5 Differences in ISQ scores between autism and neurotypical groups, high vs. low autistic traits groups, by gender

Autism and neurotypical groups						
Gender	Autism group		Neurotypical group		95% CI	Cohen's *d*
	Mean	SD	Mean	SD		
Males	91.39	24.49	49.05	23.55		
Females	87.74	31.06	47.08	23.10		
Combined	89.37[a]	27.47	47.82[b]	23.26	[34.72, 48.36]	1.63
High autistic traits vs. low autistic traits groups						
Gender	High autistic traits		Low autistic traits		95% CI	Cohen's *d*
	Mean	SD	Mean	SD		
Males	65.97	28.04	38.08	13.22		
Females	66.31	31.08	41.82	18.94		
Combined	66.86[c]	29.56	40.80[d]	17.62	[21.01, 31.11]	1.07

CI 95% confidence interval of the mean difference; [a]$n = 52$, [b]$n = 459$, [c]$n = 147$, [d]$n = 195$

a priori predictions in terms of strength and direction. The predicted correlation that openness to experience would be weakly negatively correlated with ISQ scores was not supported (correlation was non-significant). Alexithymia was strongly positively correlated with interoception difficulties, which was in the predicted direction but with a magnitude that is stronger than expected.

Extraversion and body listening were weakly inversely correlated with interoception difficulties. Body listening being weakly inversely related was as predicted regarding strength and direction. Agreeableness, conscientiousness, attention regulation, emotional awareness, and self-regulation were all moderately inversely correlated with interoception difficulties. Four predictions were supported

Table 6 Percentage of adults with ISQ scores greater than 1 standard deviation above neurotypical mean, by group

Number	Neurotypical (%)	Low autistic traits (%)	High autistic traits (%)	Autism (%)
1 *SD* (≥71 on ISQ)	19	9	45	74
2 *SD* (≥94 on ISQ)	4	0.01	19	46

SD standard deviation, *ISQ* Interoception Sensory Questionnaire

(conscientiousness, attention regulation, emotional awareness and self-regulation). Finally, neuroticism was moderately positively correlated with interoception difficulties, which is consistent with the predicted strength and direction. Confusion about interoceptive bodily states remained strongly positively correlated with alexithymia, after controlling for age, gender and years of education ($r = .76$, $p < .001$).

Divergent Validity

To assess divergent validity, further correlational analysis was conducted between the ISQ and participants' years of education and gender. Confirming predictions, neither years of education ($r \leq .01$; $p = .960$), nor gender ($r_{pb} = -.03$, $p = .566$) were significantly correlated with the ISQ. Using separate independent samples *t*-tests, the mean differences between males and females on ISQ scores was not statistically significant in the neurotypical group $t(457) = 0.88$, $M_{diff} = 1.96$, 95% CI [−2.44, 6.37], $p = .382$], the low autistic traits group $t(193) = -1.32$, $M_{diff} = -3.74$, 95% CI [−9.32, 1.84], $p = .188$], the high autistic traits group $t(140) = -0.07$, $M_{diff} = -0.35$, 95% CI [−10.40, 9.71], $p = .946$] or the autism group $t(48) = 0.46$, $M_{diff} = 3.65$, 95% CI [−12.46, 19.76], $p = .651$] (Table 7).

Discussion

The current study aimed to develop a self-report measure for adults that is maximally sensitive to the specific interoception challenges of people with autism (i.e., discriminated between autistic and non-autistic experiences). With item development based on the salience theory of interoception (Uddin and Menon 2009; Uddin 2015), qualitative analyses of online vlogs and semi-structured interviews with adults on the autism spectrum (Fiene 2018), it was anticipated that this scale would be able to operationalise variance in the recall of experiences of interoceptive challenges in adults on the autism spectrum. As this is a relatively new construct, the current scale-design was necessarily exploratory in nature.

Results showed that the ISQ is a reliable instrument for measuring interoceptive confusion in adults with autism, with evidence of a one-factor structure. Analyses showed that the 20-item ISQ possesses adequate convergent and discriminative validity, as well as excellent internal consistency ($\alpha = 0.96$). A further aim was to develop a measure that was also able to capture variation in interoception that was relevant to the differences between adults high and low on autistic traits, consistent with the hypothesis that autism is the extreme end of a dimension of autistic traits that runs through the general population (Ruzich et al. 2015). The final aim was to conduct preliminary assessment of the scale's construct validity, internal consistency, convergent and discriminant validity.

The findings from the item screening analysis and factor analysis suggest that the construct best discriminating between autistic and non-autistic experiences is confusion about interoceptive bodily states unless those states are extreme. This is a type of Alexisomia, where somatic awareness only becomes clear once interoceptive bodily signals are strong. Indeed, Alexisomia has previously been theorised to be linked with homeostatic behavioural challenges as well as Alexithymia (Kanbara and Fukunaga 2016). It has been found that the strongest discriminators of autistic vs. non-autistic experiences represent (a) challenges with identifying and describing bodily states (b) not feeling the affective/motivational components to act upon bodily states and (c) externally cued physiological self-regulation.

It was predicted that there would be a moderate to strong positive correlation with the TAS-20 Alexithymia scale in the convergent validity analyses of the ISQ. The higher than

Table 7 Correlations between ISQ and convergent validity measures

	TAS-20	BFI extraversion	BFI agree	BFI Consc	BFI neurotic	BFI open	MAIA—attention regulation	MAIA—emotional awareness	MAIA—self regulation	MAIA—body listening
ISQ	0.76	−0.17	−0.32	−0.28	0.33	−0.05[a]	−0.28	−0.24	−0.26	−0.15
Sig	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p = .273$	$p < .001$	$p < .001$	$p < .001$	$p = .001$

ISQ Interoception Sensory Questionnaire—20 items, *TAS-20* Toronto Alexithymia Scale, *BFI* Big Five Inventory: extraversion vs. introversion, agreeableness vs. antagonism, conscientiousness vs. lack of direction, neuroticism vs. emotional stability, openness vs. closedness to experience, *MAIA* multidimensional assessment of interoceptive awareness

[a]Correlation not consistent with hypothesised strength and direction

expected correlation between Alexithymia and interoceptive confusion (Alexisomia), shows that the two constructs are more closely related than we initially expected. Awareness of the changes in the physiological condition of the body (thirst and hunger etc.) and awareness of changes in emotional states are strongly linked constructs. However, while it has been suggested that interoceptive awareness is fundamental for emotional awareness (Craig 2015; Kanbara and Fukunaga 2016), it is unclear whether one facilitates the other or how this might occur. Nonetheless, it is clear that further research is required to elucidate the relationship between Alexisomia and Alexithymia.

The findings from this study have also identified that interoceptive confusion is reported in 74% of adults with autism, defined as an ISQ score of one *SD* above the neurotypical mean (≥ 71). This indicates there is also a sub-group of adults (26%) who did not report experiencing interoceptive confusion in this current study. This is an important finding, and is consistent with prior studies on external sensory perception in adults.

Relative item loadings and the pattern of validity correlations suggests that cognitive processes are involved with interoceptive confusion, however questions regarding the exact nature of these cognitive influences remain. Specifically, it is unclear whether confusion is generated by way of top-down weak prior predictions (i.e. generating inconclusive predictions of expected interoceptive states) or whether cognitive confusion is the result of aberrant feed-forward interoceptive homeostatic pathways. Indeed, it may be that cognitive strategies such as external cue reliance have developed as a vicarious function of an aberrant interoceptive network and that disruptions of the salience network have led to a distorted awareness of internal/external stimuli.

Another finding of the study is that adults high in autistic traits also appear vulnerable to disturbances of the interoceptive sense, and this is consistent with prior studies on external sensory perception (Robertson and Simmons 2015). This raises the question of whether sensory challenges indicate the presence of a categorical diagnosis of autism or whether they are an aspect of severity of autistic traits across the broader autism phenotype. Nonetheless, it is apparent that adults with autism experience the most severe interoceptive challenges, an important finding from the study.

Limitations and Clinical Implications

This study suffered from several limitations that need to be acknowledged. The convenience sampling and the exclusive reliance on self-report data for measurement of validity constructs (including a diagnosis of Autism) limit confidence in the current findings. Cross-validation studies are required to further confirm the validity of the 20-item ISQ in autistic and neurotypical populations. With respect to the use of self-report scales, the study of interoception is a new area of research in the field of psychology and autism, and it is important to initially understand the lived experiences of individuals, by way of interviews and self-report scales to gain information about health-related behaviours and events. Experimental designs alone cannot tell us, for example, why an individual may struggle with physiological self-regulation. Self-report scales can tell us quantitatively the extent than an individual perceives any difficulties as they are outlined in the set of items. These data will form an important part of a larger picture that will also involve experimental data and qualitative data. As such, self-report of interoceptive experiences has an invaluable clinical and research application. This is the strength of this exploratory approach. While it is true that the construction of such an instrument relies on the assumption that adults with ASD have good enough self-awareness to identify their own aberrant interoceptive ability, we believe that the results clearly show this assumption is supported.

An inability of adults with ASD to identify their own aberrant interoceptive ability would lead to either meaningless responses or a systematic response set reflecting something like common method variance or possibly acquiescence bias. However, these types of biases cannot explain the pattern of correlations observed with converging and diverging constructs. For example, the presence of both a very strong correlation with TAS-20 and no correlation with openness to experience is a pattern that refutes the possibility of meaningless responses and response sets. The correlation with TAS-20 is too strong to be the product of common method variance, and if common method variance is responsible for this large correlation, it would also similarly artificially inflate the correlation with openness to experience (as would a response set like acquiescence bias). The most plausible explanation for the pattern of results observed is that the new scale is reliably and validity measuring interoception, and by extension that adults with ASD have good enough self-awareness to identify their own aberrant interoceptive ability.

The present findings have several key clinical implications. The 20-item ISQ provides a preliminary framework for health practitioners to organise and anticipate the types of challenges adults with autism, and those high in autistic traits, might face. The items referencing difficulties defining or describing internal sensory experiences also highlight unique challenges for health practitioners by complicating clinical presentations. For example, difficulties describing, or even misinterpreting specific interoceptive signals can increase the chances patients and health practitioners overlook or mistake health conditions; particularly conditions for which specific interoception signals are relied upon as key indicators (such as cardiac arrhythmias or appetite loss). For patients with interoception challenges, practitioners should

seek to corroborate reports of internal sense experiences. Items contained within the ISQ also reference how interoception challenges have implications for physiological self-regulation. While many with autism and those high in autistic traits have developed skilful externally-cued strategies in attempt to physiologically self-regulate (Fiene 2018), the inability to rely on interoceptive signals present important physical health risks that, in extreme cases, could conceivable lead to severe dehydration, heat exhaustion, or malnutrition. These implications also further highlight the need for a valid measurement tool that is capable of capturing variance in interoceptive difficulties. Such a tool would aid health practitioners as well as researchers in developing a more complete understanding of interoception and related difficulties and provide useful benchmarks against which interventions could be evaluated.

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Compliance with Ethical Standards

Conflict of interest There are no conflicts of interest.

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