Investigating eye examination-related anxiety in autistic adults

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RESEARCH

Investigating Eye Examination-Related Anxiety in Autistic Adults

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Abstract

Clinical relevance: It is important to investigate whether anxiety is a barrier to accessing eye examinations for autistic adults, because existing research suggests this population are more likely to develop ophthalmic abnormalities.

Background: Anxiety influences healthcare accessibility for autistic people without learning disabilities. Previous qualitative studies by the research team, with a small sample of autistic adults, have indicated several aspects of eyecare services which cause anxiety. Considering the limited existing research, suggesting autistic individuals are more likely to develop ophthalmic abnormalities, this study explored whether this population more widely experiences anxiety when accessing eye examinations.

Methods: A total of 322 UK-based autistic adults completed the Optometric Patient Anxiety Scale (OPAS) online, between July and December 2020. The responses were Rasch analysed to firstly validate this questionnaire for an autistic adult population, and then make a comparison of optometric anxiety levels to the general population.

Results: Item infit (0.77 to 1.39) and outfit (0.78 to 1.33) values, the person separation index (2.64), and item (0.99) and person (0.97) reliability coefficients suggested that all 10 items in the OPAS are useful to assess optometric anxiety in an autistic adult population. Item probability curves confirmed the response scale to be appropriate. A comparison of optometric anxiety between the autistic population in the current study and a general population in previous work found no statistically significant difference.

Conclusion: The OPAS is a statistically valid tool for use in the autistic adult population. It

appears to suggest no significant difference in optometric anxiety between the autistic adult and general population. However, it is possible that it underestimates the true optometric anxiety of autistic adults since the items do not include some of the anxiety provoking factors for this population which have been indicated in previous studies by the research team.

INTRODUCTION

Autism is a lifelong neurodevelopmental condition, affecting approximately 1.1% of adults[1] and 1.57% of children[2] in the UK. Autistic individuals can display altered social interaction, communication and behaviour which form part of the UK diagnostic criteria, laid out in the International Statistical Classification of Diseases (ICD-11)[3] and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).[4] Additionally, the majority of autistic people experience altered sensory reactivity[5] and display sensory-seeking behaviours.[6]

Compared to 5% in the general population,[7] recent systematic reviews and meta-analyses have reported about 42% of autistic adults[8] and 40% of autistic youth[9] had suffered an anxiety disorder in their lifetime. This included specific phobias, generalised anxiety, panic and social anxiety. However, these figures could be underestimated because, as described in the DSM-5,[4] autism and anxiety disorder are often challenging to separate. Furthermore, autistic people generally have difficulty recognising, understanding and describing their emotions, and social communication deficits may limit their ability to effectively communicate these.[10,11] Interestingly, anxiety most commonly co-occurs with hypersensitivity in autism,[12,13] although the link between the two is not clear.[14]

Amongst the limited literature, anxiety has been identified as an influential factor in the accessibility of healthcare services for autistic people. Surveying 209 autistic adults with the Barriers to Healthcare Checklist, Raymaker et al[15] found the top barrier to be 'fear and anxiety'. Dern and Sappok[16] conveyed the outcomes of discussions between autistic adults and autism professionals, reporting stress due to uncertainty, and anxiety meeting unfamiliar staff, as some examples of healthcare barriers. Furthermore, Saqr et al[17] conducted focus groups with autistic adults who summarised 'anxiety from waiting' as a factor which stressed this population during a healthcare appointment.

If anxiety was restricting access to eyecare for this population, this would be a particular cause for concern. Although limited to a small number of studies, mainly involving children and adolescents, research has concluded autistic individuals are at greater risk of developing ophthalmic abnormalities such as refractive error, strabismus and amblyopia.[18] The upper age limit amongst these studies was 20 years: assuming these findings also reflect the optometric status of autistic adults, we can expect autistic people to need to visit an optometrist regularly.

The aim of this study was therefore to investigate whether anxiety may be a barrier to eye examination accessibility for autistic adults without learning disabilities. To capture a large and geographically diverse population, an online survey was carried out using the Optometric Patient Anxiety Scale (OPAS).[19] Court et al[19] had identified the detrimental effects anxiety can have on healthcare outcomes for the general population. As this subject had previously received little attention in the eyecare sector, they developed and validated the first anxiety survey for a general population in an optometric setting. The survey items (Table 1) probe a variety of potentially anxiety-provoking situations related to test procedures, eye health and

patient-practitioner relationship. The current study validated the OPAS for an autistic adult population and subsequently made a comparison to the general population.

In earlier studies conducted by the research team,[20] focus groups and interviews with a total of 42 autistic adults were conducted to explore the barriers for autistic individuals accessing eye examinations, and to develop recommendations to improve the autistic patient experience. Findings suggested eyecare services are not very accessible for autistic adults without learning disabilities, with some of our participants avoiding eye examinations. Unsurprisingly, many aspects of an eye examination were unpleasant sensory experiences for participants (bright lights and physical contact with instruments), and tests requiring close practitioner proximity were uncomfortable. It was therefore reasonable to suggest that this would manifest as creating eye examination-related anxiety. The research team hypothesised that autistic adults without learning disabilities would show a higher level of anxiety than the general population.

METHODS

Recruitment and participants

Inclusion criteria were: formal diagnosis as autistic, absence of a learning disability, aged 18 years or over, being a UK resident, having had a previous UK eye examination and access to the internet. Compliance with these criteria could only be judged by participant self-report.

The study was publicised on the research project website (sites.manchester.ac.uk/autism-and-vision/), and by email and social media (Facebook and Twitter) using the Autism@Manchester network, university platforms and autism groups. The advert contained

the survey link where potential participants were able to access study information and details of how to contact the research team. Before proceeding to complete the survey, participants had to confirm, by clicking a tickbox, that they met the inclusion criteria and consented to taking part in the study. The survey was active from July to December 2020, and all responses were anonymous.

Prior to commencing the study, the Autism@Manchester Virtual Expert by Experience Group (www.autism.manchester.ac.uk/connect/expert-by-experience/) trialled the survey and provided feedback on its accessibility for our target population. This study received ethical approval from The University of Manchester's Research Ethics Committee (2020-9668-15811).

Survey content and procedure

The survey began by asking participants for background information: gender, age, autism diagnosis (with date and clinic name), date of last eye examination, and brief ocular history. Participants then had to actively go to the next page of the survey (by clicking "next") which presented the OPAS (Table 1). The participant instructions, items, item order and response options were mirrored from the original questionnaire.[21] Each of the 10 items had four response options: strongly agree, agree, disagree, strongly disagree.

[TABLE 1 HERE]

Upon completion of the survey, participants could optionally provide their email address to enter a prize draw. Finally, they were thanked for their participation and signposted to support charities or their GP if they felt distressed due to the survey.

Statistical analysis

Following the methodology used by Court et al,[19] questionnaire responses were Rasch analysed in the current study. This is a branch of item response theory, used to overcome some of the limitations of traditional questionnaire scoring. This analysis does not assume that all items should contribute equally to the final score, or that the steps in the Likert scale are of equal intervals.[22]

An opportunity sample was recruited for this study. Although a target sample was not statistically calculated, the research team aimed to obtain 100-200 responses; samples of less than 100 participants have been found to yield opposite Rasch analysis results.[23] Rasch analysis quantifies latent traits ('anxiety' for the current study) based on the assumption that a participant response to an item is a function of the difference between their ability (their level of anxiety in the current study) and the difficulty of the item (the level of anxiety captured by the item).[24] Rasch analysis produces logit values which describe these factors; to place our findings into context we wanted to compare our logit values which represent autistic adults without learning disabilities, against those from Court et al[19] which represent a general population.

The data were organised by listwise deletion of incomplete responses and removal of responses from participants who did not meet the inclusion criteria, and Rasch analysed using jMetrik (version 4.1.1). The remainder of this section describes how the outputs of this analysis were used.

Firstly, the validity of the OPAS for an autistic adult population, without learning disabilities, was assessed. This was to ensure the situations described by the items together with the

response options effectively covered the same range of anxiety as are experienced by this population when attending for an eye examination.[25]

Using item probability graphs, the response scale was examined to ensure an appropriate number of response options which autistic adults could reliably discriminate between. Fit statistics (infit and outfit) were used to judge how accurately the individual survey items fit the unidimensional nature of the Rasch model.[26] The ideal fit statistic value is 1, signifying the item is perfectly unidimensional and effectively measures the underlying latent trait.[19] But, as per Linacre,[27] values between 0.5 and 1.5 are acceptable as this suggests the item is productive for measurement. Values outside this range can imply the item is less productive for measurement and can degrade the measuring tool.[27]

The ability of the survey to efficiently separate respondents with differing levels of anxiety was determined by the person separation index, which should be greater than 2.[25] Finally, the reliability of the OPAS, in the context of an autistic adult population, was determined using the person and item reliability statistics.

RESULTS

Descriptive statistics

A total of 367 survey submissions were received. Two were removed because they did not meet the inclusion criterion of a confirmed autism diagnosis. Furthermore, 43 incomplete submissions, which did not include responses to the OPAS, were removed by listwise deletion. Therefore, the final sample contained 322 acceptable and complete responses. All participants declared a confirmed diagnosis of an autism spectrum condition (Asperger's/

200 autism/ autism spectrum condition/ autism spectrum disorder) and 319 also provided further
201 details: diagnosis date, diagnosing clinician and clinic.
202
203 [TABLE 2 HERE]
204
205 Table 2 presents the gender, age, ocular history and last eye examination information of these
206 participants. Most responses were received from females, approximately twice those received
207 from males. Although responses were received from all age categories, the mean was 30-39
208 years.
209
210 **Response scale analysis**
211 Using item parameters, probability graphs were plotted for each item and used to judge the
212 response category calibration. There was no significant difference visually between the 10
213 probability curves plotted for our analysis; Figures 1a and 1b are the probability graphs for
214 items 1 and 2, respectively. Items 1, 6, 9 and 10 are positively worded, whereas the remaining
215 items are negatively worded. Therefore, the scoring is reversed for the former so that overall,
216 a higher OPAS score would represent higher optometric anxiety.
217
218 [FIGURE 1a AND 1b HERE]
219
220 Firstly, it is important the response options are plotted in order progressively along the x-axis;
221 that is, as participant anxiety increases (theta), they are more likely to choose the next
222 response option. Secondly, each response option curve should have a distinct peak; this
223 means each should have a point or range of anxiety where it is most likely to be selected. All
224 our probability graphs conformed to these two conditions, as exemplified by Figures 1a and

1b. Hence, the response scale was deemed useful, well calibrated and appropriate for an autistic adult population.

Item analysis

Item statistics (Table 3) were used to identify any items which misfit the Rasch model.

[TABLE 3 HERE]

Infit values ranged from 0.77 to 1.39; outfit values ranged from 0.78 to 1.33. Both comply with the recommendations of Linacre[27] suggesting all the items are productive for measurement and fit the unidimensional Rasch model well. It was concluded that all the items in the OPAS were useful to assess optometric anxiety of autistic adults.

Person and item estimates

A person-item anxiety distribution map was plotted (Figure 2) which shows the distribution of person ability (left side) and item difficulty (right side) estimates on one logit scale. This allowed description of the range of optometric anxiety in an autistic adult population (-6.27 to 4.43 logits, mean= -0.1558 (SD ±1.74), root mean square error (RMSE)= 0.52) versus the range of anxiety captured by the items (-5.25 to 4.90 logits, discrepancy of means= 5.55, RMSE=0.09). The item difficulty map shows the range and mean anxiety levels measured by each item. Overall, the items appear to be targeted slightly towards the higher levels of anxiety, nevertheless they cover almost the full range of person anxiety levels.

[FIGURE 2 HERE]

The measurement precision of this survey was confirmed by the high item and person reliability coefficients, 0.99 and 0.87 respectively. Furthermore, the person separation index was 2.64, indicating this survey can discriminate well between autistic persons with differing levels of optometric anxiety.

Comparison of optometric anxiety levels

In the present study, the person ability graph (see Figure 2) plotted the distribution of estimated optometric anxiety levels in the autistic adult population. To consider this in perspective, it was compared against person ability estimates from Court et al,[19] who originally validated this survey for a general population. Therefore, a comparison of optometric anxiety levels between autistic adults without learning disabilities and the general population could be made. To do this, firstly, the person ability (anxiety) estimates distribution from the current study and Court et al[19] were plotted on equivalent axes (Figure 3). The raw data from Court et al[19] were not available, and therefore were interpreted from Figure 3 in their published paper.

[FIGURE 3 HERE]

It can be seen that both distributions peak at approximately zero and have a similar range. A Kolmogorov-Smirnov test confirmed the person abilities were not normally distributed in either study. The median was 0.0707 (interquartile range: 1.8381) and 0 (interquartile range: 2.8000) for the current study and Court et al,[19] respectively. Although person ability medians suggested that autistic adults without learning disabilities experience slightly higher optometric anxiety than the general population, an independent samples Mann-Whitney U

test confirmed there was no statistical difference between the person ability distributions of the two studies ($U(n_{current\ study}=322, n_{Court\ et\ al}=135)=20995$, $z=-0.816$, $p=0.415$).

DISCUSSION

The current study investigated whether autistic adults without learning disabilities experience greater optometric anxiety compared to the general population. To the knowledge of the research team, this was the first survey study which explored this. Considering the findings of previous studies by the research team,[20] and that anxiety has been indicated to be one of the most common mental health conditions in the autistic population,[28] it was hypothesised that participants in the current study would be more anxious about eye examinations compared to the general population.

Court et al[19] developed the first Optometric Patient Anxiety Scale, which was validated for a general population using Rasch analysis. This statistical method allowed them to confirm that the survey items were unidimensionally measuring anxiety, the response options were well calibrated and the range of anxiety captured by the items well-matched the distribution of anxiety in this population. Using the same approach in the current study, analysis of the response scale, items and person and item estimates supported the validity of the OPAS for an autistic adult population without learning disabilities. This generalisation could be made as Rasch analysis is independent of the sample data to which it is applied, therefore the results can be applied to the population in question.[22]

One of the outputs of Rasch analysis is a person-item distribution map, on which the 'person ability' distribution is suggested. This represented optometric anxiety in the autistic adult and

298 general populations, in the current and Court et al[19] study respectively. Therefore, a direct
299 comparison of optometric anxiety levels between the two populations was possible.
300 Comparison of median optometric anxiety levels suggested that autistic adults are slightly
301 more anxious about attending for an eye examination compared to the general population.
302 However, statistical analysis confirmed that there was no significant difference between
303 optometric anxiety in the two populations.
304
305 Similarities and differences can be found between the samples of the current and Court et al[19]
306 study. Firstly, over twice the number of participants took part in the current study (322)
307 compared to a sample of 141 participants in Court et al.[19] Therefore, the outcomes of the
308 current study cannot be explained by insufficient data. Next, a similar proportion of males
309 and females took part in both studies (Court et al[19]: male= 35.5%, female= 64.5%); Court et
310 al[19] did not capture information about other gender groups. Additionally, the proportion of
311 participants requiring a spectacle prescription was similar (current study: 82.6%, Court et
312 al[19]: 81%). Finally, the mean age of participants in Court et al[19] was slightly higher at 43.21
313 years (30-39 years in the current study) and they recruited their participants between four
314 optometric practices; the current study is likely to have captured a relatively larger
315 geographical representation. Overall, our surprising findings cannot be attributed to the
316 demographics of the sample.
317
318 Although the hypothesis of the current study was proven incorrect, it is possible that autistic
319 people who were more anxious did not respond to the survey or had never been for an eye
320 examination. However, it is also possible that autistic individuals who experienced no anxiety
321 related to eye examinations may not have responded, believing that their responses were not
322 relevant.

In a previous focus group study by the research team,[20] some participants suggested that they delayed their healthcare appointments for as long as possible due to anxiety. Considering the demographic data of participants in the current study, only 8.4% of them had undergone an eye examination more than 2 years ago. Therefore, individuals who 'put off' eye examinations may not have been recruited, since this figure compares favourably with the 27% of the general UK population whose last examination was more than 2 years ago.[29] It is possible that targeting the group of autistic individuals who have delayed their eye examinations, or never had one, would have identified higher levels of optometric anxiety.

The OPAS may not be capturing the causes of anxiety for some autistic adults when they attend for an eye examination. Considering the 10 items included in the OPAS, it is apparent that these are focused on what the patient will experience in the testing room; items relating to the practice environment ("the environment at the Optometrist's makes me feel uneasy") and spectacle dispensing ("I am anxious that I will have to purchase a new pair of spectacles") were eliminated during the developmental process.[19] Rather than including items which covered all areas of an eye examination which may be anxiety provoking, Court et al[19] developed the OPAS as a tool which could identify anxious optometric patients as opposed to determining the causes of optometric anxiety. From previous work by the research team,[20] it is clear that factors across the whole of an eye examination visit, beginning from booking the appointment, and when entering the practice through to the final spectacle dispense, influence optometric anxiety levels for autistic people. Reluctance to book appointments over the phone, the retail environment in the practice, and having to meet multiple members of staff during the appointment, are examples of factors identified by participants in Parmar et al[20] which would not be captured by the OPAS. The outcomes of the current study therefore

suggest that optometric anxiety levels were similar to those in the general population because several key areas which provoke anxiety for autistic people during an eye examination are not covered by the OPAS items.

This raises the question as to whether other currently available healthcare anxiety scales are suitable to capture the anxiety of autistic patients. For example, the Surgical Anxiety Questionnaire[30] and Surgical Fear Questionnaire[31] mainly focus on anxiety provoking factors post-surgery: experiencing post-operative pain, having to take time off work, and not recovering from the procedure. Analogous to the OPAS, neither of these mention anxiety provoking factors in the lead up to the surgery or associated with the hospital environment. However, the Dental Anxiety Scale-Revised[32] does focus on some factors outside the dental consultation, such as how one may feel prior to attending the appointment or whilst in the waiting room. Encouragingly, it also asks patients about how anxious they may feel about individual procedures including fillings, injecting local anaesthetic and tooth extraction. This could be useful for practitioners as they may be able to get an idea of any altered sensory sensitivities or stressing factors which the autistic patient would experience. Moreover, it is more likely to correctly assess the healthcare anxiety of autistic people by mentioning factors important for this population.

Limitations and recommendations

As this was an online study, participants were self-selecting, which can induce sampling bias. Participants were limited to those who could access the internet. However, as per the Office for National Statistics,[33] 92% of UK adults accessed the internet in 2020 suggesting the nature of our study did not pose any significant limitation on accessibility. Furthermore,

autistic individuals who are uncomfortable with verbal communication are more likely to have taken part in our study.

We relied on participant self-declaration of meeting the inclusion criteria. Although this could have been mitigated by asking participants to submit evidence of their age and UK residence, this would have been inappropriate within the context of an anonymous study. No proof was required of an autism diagnosis, but 99% of participants did give details of this.

Our results are representative of autistic people without learning disabilities, who make up approximately two-thirds of the autistic community.[34] It may be that autistic individuals with a co-existing learning disability experience a different degree of optometric anxiety. Finally, the gender ratio in the current study, though similar to Court et al,[19] was not representative of the autistic population. Approximately four-times more males are diagnosed as autistic than females.[35,36]

CONCLUSION

The Optometric Patient Anxiety Scale, as developed by Court et al[19] is a valid instrument for use with autistic adults without learning disabilities. But it is likely to be of limited value in this population as it does not include key anxiety-provoking items which have been highlighted in previous qualitative research.[20] As a consequence, the scale may underestimate the true optometric anxiety levels of autistic patients. This could also be the case for other available healthcare anxiety questionnaires. Optometric examinations are a source of anxiety for some autistic adults, and providers can adapt their services to reduce that anxiety: evidence-based recommendations on achieving autism-friendly eye examinations have been provided by Parmar et al.[20]

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CONFLICTS OF INTEREST

The authors report there are no competing interests to declare.

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519 TABLES

520

521 *Table 1 The 10 items in the OPAS instrument. Each item had four response options: strongly*

522 *agree, agree, disagree and strongly disagree.*

Item number	Item description
1	I feel relaxed during the eye test
2	I am afraid I will find the tests hard
3	Talking to the Optometrist makes me feel tense
4	I feel on edge during the examination in case something goes into my eye
5	I am anxious something unpleasant will happen to my eyes
6	I am content that my eyes are healthy
7	I worry about going to have my eyes checked
8	When the Optometrist is close to me I feel tense
9	I trust the Optometrist
10	I am satisfied in the ability of the Optometrist

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Table 2 Gender, age, ocular history and eye examination demographics for the final sample of 322 participants.

Variable		n (%)
Gender	Female	197 (61.1)
	Male	94 (29.2)
	Non-binary	27 (8.4)
	Transgender	2 (0.6)
	Prefer not to say	2 (0.6)
Age (Years)	18-29	101 (31.4)
	30-39	73 (22.7)
	40-49	61 (18.9)
	50-59	56 (17.4)
	60-69	24 (7.5)
	70-79	6 (1.9)
	>=80	1 (0.3)
Ocular history	Spectacle wearer	266 (82.6)
	Contact lens wearer	36 (11.2)
	History of refractive surgery	5 (1.6)
Last eye examination	Within last 6 months	93 (28.9)
	6 months – 1 year ago	99 (30.7)
	1 – 2 years ago	103 (32.0)

	Over 2 years ago	27 (8.4)

554 *Table 3 Item statistics for the individual OPAS items: infit and outfit values.*

Item	Infit	Std. infit	Outfit	Std. outfit
1. I feel relaxed during the eye test	0.81	-2.59	0.78	-3.15
2. I am afraid I will find the tests hard	1.10	1.31	1.06	0.85
3. Talking to the Optometrist makes me feel tense	0.77	-3.11	0.78	-3.26
4. I feel on edge during the examination in case something goes into my eye	1.28	3.22	1.33	3.86
5. I am anxious something unpleasant will happen to my eyes	1.10	1.30	1.14	1.77
6. I am content that my eyes are healthy	1.39	4.30	1.18	2.19
7. I worry about going to have my eyes checked	0.85	-2.02	0.83	-2.14
8. When the Optometrist is close to me I feel tense	1.03	0.36	1.04	0.50
9. I trust the Optometrist	0.85	-1.79	0.82	-2.36
10. I am satisfied in the ability of the Optometrist	0.90	-1.07	0.84	-2.04

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FIGURE CAPTIONS

Figure 1 Item probability graph for item 1 (1a) and item 2 (1b). The x-axis represents participant anxiety levels (theta), and the 4 curves on each graph represent each response category (labelled).

Figure 2 Person-item anxiety distribution map for the OPAS. The distribution of person ability (anxiety) estimates is represented by the left-hand side histogram; 'person density' refers to the proportion of autistic adults. The item difficulty estimates, mean and range of anxiety captured by each item, are represented by the centre of the symbols on the right-hand side. Both person ability and item difficulty estimates are plotted on an equivalent logit scale on the y-axis, representing anxiety levels. Please note, the symbols in the figure are randomly allocated by the statistical software.

Figure 3 A histogram showing the distribution of person ability (anxiety) estimates for autistic adults without learning disabilities (from the current study: blue) and the general population (from Court et al[19]: orange). To be able to plot both distributions on an equivalent x-axis, person ability values for both studies were binned into the intervals shown.