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Original Research

Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder

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ABSTRACT

Research indicates significant health disparities for individuals with autism. Insight into characteristic sensory, cognitive, communication, social, emotional, and behavioural challenges that may influence health communication for patients with autism is vital to address potential disparities. Women with high functioning autism spectrum disorder (ASD) may have specific healthcare needs, and are likely to independently represent themselves and others in healthcare. A pilot study compared perceptions of healthcare experiences for women with and without ASD using on-line survey based on characteristics of ASD likely to influence healthcare. Fifty-eight adult female participants (32 with ASD diagnosis, 26 without ASD diagnosis) were recruited on-line from autism support organisations. Perceptions measured included self-reporting of pain and symptoms, healthcare seeking behaviours, the influence of emotional distress, sensory and social anxiety, maternity experiences, and the influence of autistic status disclosure. Results partially support the hypothesis that ASD women experience greater healthcare challenges. Women with ASD reported greater challenges in healthcare anxiety, communication under emotional distress, anxiety relating to waiting rooms, support during pregnancy, and communication during childbirth. Self-disclosure of diagnostic status and lack of ASD awareness by healthcare providers rated as highly problematic. Results offer detailed insight into healthcare communication and disparities for women with ASD.

1. Introduction

Qualitative reports of healthcare experiences for patients with autism spectrum disorder (ASD) (Aylott, 2004, 2010) have highlighted critical challenges linked to social, emotional, communication, sensory, and behavioural differences, compared to patients without ASD. Higher mortality and morbidity rates (Bilder et al., 2013; Mouridsen, Brønnum-Hansen, Rich, & Isager, 2008) and poorer health and social outcomes (Balfe & Tantam, 2010; Levy & Perry, 2011) are also indicated for individuals with ASD. Previous reports have emphasised health and healthcare challenges for children and lower functioning adults with ASD (Ahmedani & Hock, 2012; Kuhlthau et al., 2010; Liptak, Stuart, & Auinger, 2006; Minnes & Steiner, 2009); however, limited data is available for healthcare experiences for high functioning adults with ASD (Bruder, Kerins, Mazzeella, Sims, & Stein, 2012).

High functioning adults with ASD are more likely to represent themselves independently across all healthcare settings compared to children and low functioning adults, due to average to above average intelligence and functional language skills (Levy & Perry, 2011; Noterdaeme, Wriedt, & Höhne, 2010; Soulières, Dawson, Gernsbacher, & Mottron, 2011). Perceptions that high functioning adults have less disability-related needs (Nicolaidis et al., 2013) and poor clinician understanding of the characteristics of high functioning ASD in general medicine (Venkat, Jauch, Russell, Crist, & Farrell, 2012) may decrease health practitioner awareness of healthcare challenges for this population. This study addressed the need to understand challenges in healthcare communication for high functioning adults with ASD.

1.1 High functioning ASD communication and healthcare

Healthcare communication for adults with ASD is likely to be determined by the interaction of characteristic ASD differences and unique contexts within healthcare.

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) recognises ASD deficits in social-emotional reciprocity, understanding interpersonal relationships and non-verbal communication, and restricted and repetitive patterns of behaviour with hypo-hyper sensory reactivity to the environment, with or without intellectual and language impairments. Unique characteristics of healthcare experiences that may be problematic for patients with ASD include the need for timely and accurate communication, emotional and physical discomfort and distress, unfamiliar conversational partners, and confronting sensory environments.

1.1.1 ASD social and emotional challenges

Healthcare experiences of patients with high functioning ASD are likely to be influenced by deficits in processing emotional stimuli for self and others, expressing emotions verbally, and self-regulating emotions (Bird, Press, & Richardson, 2011; Bölte, Feineis-Matthews, & Poustka, 2008; Laurent & Rubin, 2004; Montgomery, Stoesz, & McCrimmon, 2013; Samson, Huber, & Gross, 2012). The extent to which patients with ASD experience compounding emotional challenges due to social, communication, and sensory challenges within healthcare settings is unknown. It is also unclear how their communication in healthcare settings is influenced by perceptions of stigma and discrimination relating to disclosure of diagnostic status of ASD (Butler & Gillis, 2011; Calzada, Pistrang, & Mandy, 2012; Heidgerken, Geffken, Modi, & Frakey, 2005; Huws & Jones, 2010; Shtayermman, 2007, 2009; Stevenson, Harp, & Gernsbacher, 2011).

1.1.2 ASD verbal and non-verbal communication challenges

Relatively high language skills and compensatory communication strategies developed by high functioning adults (Hobson, 2012; Lee & Park, 2007) may mask

social anxiety (Freeth, Bullock, & Milne, 2013; Kuusikko et al., 2008; Samson, Huber, & Ruch, 2011) and a range of potential communication challenges. Communication challenges may include expressive and receptive speech deficits (Holdnack, Goldstein, & Drozdick, 2011; Lewis, Woodyatt, & Murdoch, 2008; Noterdaeme, et al., 2010), speech sound disorders (Shriberg, Paul, Black, & Santen, 2011), and semantic processing differences (Gold, Faust, & Goldstein, 2010; Hobson, 2012). Non-verbal skill deficits may include processing of facial expressions and prosody (Doi et al., 2013), and speech and gestures (Silverman, Bennetto, Campana, & Tanenhaus, 2010). Further, ASD patients may have impaired ability to understand shared beliefs, knowledge, intentions, and motivations of healthcare communication partners through reduced theory of mind skills (Baron-Cohen, Leslie, & Frith, 1985; Beaumont & Newcombe, 2006).

1.1.3 ASD sensory challenges

Unique sensory experiences in healthcare environments, such as bright lights, chemical odours, and intimate physical contact may be challenging for patients with ASD who experience multisensory differences (Ben-Sasson et al., 2009; Lai et al., 2011; Magnée, de Gelder, van Engeland, & Kemner, 2011). The communication of pain and symptoms are important aspects of healthcare, yet the understanding of subjective pain and sensory experiences in ASD also remains contentious (Cascio et al., 2008; Lévesque, Gaumond, & Marchand, 2011). The influence of potential sensory challenges on healthcare experiences and behaviours of ASD adults who represent themselves independently in healthcare remains unknown.

1.1.4 ASD healthcare behaviour patterns

Although the interaction of social-emotional, communication, and sensory challenges will depend on individual deficit patterns, any associated healthcare

challenges may result in problematic behaviours such as delay in seeking healthcare, and avoidance of general or specific service providers and settings. Repeated non-disclosure of ASD diagnostic status may prevent or delay appropriate communication accommodations by service providers and may influence clinical reasoning given the potential comorbidity of various psychiatric and physiological conditions with ASD (see Bruder, et al., 2012; Memari, Ziaee, Mirfazeli, & Kordi, 2012).

1.2 Healthcare Communication Research for ASD Adults

Previous quantitative research of high functioning adults with ASD reported significantly lower perceptions of self-efficacy and satisfaction with healthcare provider communication, and disparities in unmet healthcare needs, compared to other adults (Nicolaidis, et al., 2013). However, these important findings were based on adaptation of large-scale general population healthcare surveys which may not account for characteristic social, emotional, communication, sensory, and behavioural challenges acknowledged for patients with high functioning ASD (Aylott, 2004, 2010).

Some traditional measures may be inappropriate for use with high functioning ASD populations. For example, questionnaire items requiring recall over the past year utilize skills that are potentially atypical for adults with high functioning ASD. An item such as “*Healthcare providers gave me the chance to ask all health related questions I had*” over 12 months requires adequate cognitive processing of experiences as they happen, plus accurate long-term recall. The perceptions of health communication experiences for high functioning ASD patients may be influenced by differences in auditory working memory, processing speed, and verbal comprehension (Holdnack, et al., 2011; Lewis, et al., 2008).

This type of evaluation also demands understanding of non-verbal and verbal cues. However, cue processing could be reduced through impaired integration of facial expressions and prosody (Doi, et al., 2013), impaired processing of speech and gestures (Silverman, et al., 2010), and the influence of theory of mind deficits (Baron-Cohen, et al., 1985; Beaumont & Newcombe, 2006). Additionally, being provided the chance to ask any health related questions does not guarantee patients' appropriate use of such opportunities.

Investigative tools adapted for the needs of high functioning adults with ASD are therefore required.

1.3 ASD gender differences

Previous research supports the exploration of healthcare perceptions for ASD populations by gender (Bölte, Duketis, Poustka, & Holtmann, 2011; Lai, et al., 2011; Lemon, Gargaro, Enticott, & Rinehart, 2011). Women may be more likely to engage in healthcare due to gynaecological and obstetric needs and through representing other family members, such as children and the elderly. High functioning women with ASD are also less likely to be diagnosed with autism than men (Lai, et al., 2011; Wing, Gould, & Gillberg, 2011), attributed partially to greater skills in masking autistic deficits (Kirkovski, Enticott, & Fitzgerald, 2013). The masking of characteristic ASD deficits may complicate communication for high functioning ASD women in healthcare settings, particularly if these patients do not disclose that they have an ASD diagnosis.

1.4 Present study

This pilot study aimed to address gaps in current literature and provide initial regional data that reflects Australian social, economic, political, and healthcare contexts. It formed the initial stage of development of a questionnaire to compare

healthcare experiences of women with and without high functioning ASD based on characteristic differences of autism likely to influence healthcare experiences. It was hypothesised that women with high functioning ASD would report greater healthcare challenges compared to women without ASD in both general and maternity healthcare, and be influenced by perceived stigma.

2. Materials and Methods

Participants (N = 58) were recruited through a specialist ASD psychology clinic and two local not-for-profit organisations that support individuals diagnosed with high functioning ASD and their families. Details of the on-line survey and links required to access the electronic survey were placed within the clinic and organisational web sites and client newsletters. Paper-based surveys with postage-paid return envelopes were available at organisational sites upon request. The survey was otherwise conducted and stored using secure institutional survey software.

Individuals over the age of 18 years were invited to participate, and no other restrictions applied. Participants with ASD were women who reported diagnosis of autism, Asperger's Syndrome, High Functioning Autism, or Pervasive Developmental Disorder Not Otherwise Specified (N = 32). Participants without ASD were adult female carers and family members of children or adults with ASD who did not have any ASD diagnosis (N = 26). This was to provide an independent variable control group to enable statistical analyses of between-group differences. Recruitment through the selected organisations was also expected to minimise inclusion of women with undiagnosed ASD in the control group given likely increased exposure to diagnostic opportunities.

Participants' demographic data were screened and they were excluded from analyses if they reported any communication impairments unrelated to ASD, or if

English was not their first language. The groups were considered to be comparable for age categories, with no controls required for potential age-related communication or sensory differences due to lack of participants over age 65. Participation was voluntary and anonymous. Participants were not matched for income as Australian Medicare and disability support generally enable access to healthcare. Table 1 shows participant information for general healthcare experiences survey items.

Table 1.
Participant Characteristics - General Healthcare Experiences

	Non-ASD (N = 26)	ASD (N = 32)
Age		
18 – 24 years	2 (7.7%)	2 (6.3%)
25 - 34	3 (11.5%)	5 (15.6%)
35 - 44	8 (30.8%)	7 (21.9%)
45 – 54	10 (38.5%)	13 (40.6%)
55 - 64	2 (7.7%)	5 (15.6%)
65 and over	-	-
Missing	1 (3.8%)	-
Education attained		
Secondary school to Year 10/Junior	3 (11.5%)	4 (12.5%)
Secondary school to Year 12/Senior	3 (11.5%)	3 (9.4%)
Diploma/Trade Certificate	4 (15.4%)	9 (28.1%)
University Degree	7 (26.9%)	10 (31.3%)
Post-graduate Tertiary	8 (30.8%)	6 (18.8%)
Missing	1 (3.8%)	-
Annual Household Income		
\$0 – 20,000	1 (4.2%)	6 (18.8%)
\$20,001 – 40,000	-	5 (15.6%)
\$40,001 – 60,000	3 (11.5%)	6 (18.8%)
\$60,001 - 80,000	5 (19.2%)	1 (3.1%)
\$80,001 – 100,000	6 (23.1%)	7 (21.9%)
\$100,001 – 120,000	4 (15.4%)	4 (12.5%)
\$120,001 – 150,000	2 (7.7%)	1 (3.1%)
> \$150,000	3 (11.5%)	-
Missing	2 (7.7%)	2 (6.3%)
Mean (SD) number of householders supported by income	3.17 (1.47)	2.64 (1.68)

Note: ASD = autism spectrum disorder

2.1 Procedures

Research approval was obtained from the Institutional Research Ethics Committee, and participants acknowledged informed consent via electronic submission of the survey.

2.2 Measures

The exploratory questionnaire was developed using a collaborative and iterative approach through consultation with clinicians, reviews of the current literature, and qualitative feedback from women diagnosed with high functioning ASD who were members of a local ASD support organisation that was independent from the recruiting organisations. Member feedback was provided during facilitated focus group discussions of healthcare service challenges.

2.2.1 Questionnaire constructs

Sixteen general healthcare questionnaire items [item number in parenthesis] measured experiences based on social contact [1, 11], emotion [8], communication [1, 3, 4, 5, 12, 15], sensory experiences [9, 10, 14], and behaviour [2, 6, 7, 13, 16]. Five further items measured 5 maternity healthcare perceptions relating to access to resources, communication, and behaviour. General and maternity healthcare items were designed as dependent variables for between-group analyses.

An additional 7 items, available only to participants who indicated an ASD diagnosis, measured perceptions relating to disclosure of ASD diagnostic status in healthcare settings for insight into stigma and discrimination.

2.2.2 Questionnaire item development

First person wording focused on general perceptions, rather than evaluations of specific events, to minimise the influence of potential information processing and recall difficulties. Unidimensional phrase completion scales were used for most non-demographic variables to minimise complex multidimensional cognitive processes, central tendency bias, and skipped items associated with traditional Likert scales (Hodge & Gillespie, 2003; Hodge & Gillespie, 2007). For example, “*When I am asked to verbally describe pain I...*” is completed on an interval scale from “0 (*Never*

have difficulty)” to “10 (*Always have difficulty*)”. This mimics “*on a scale of 1 to 10*” questions, with the benefit of an absolute zero point. Alternatively, it symbolises percentages whereby 5 is 50% or half the time/experiences/behaviours.

Phrase completion scales were also expected to minimise lengthy deliberation over content and potential focus on negative healthcare experiences via negativity bias (Baumeister, Bratslavsky, Finkenauer, & Vohs, 2001). One diagnostic disclosure item required a “*True/False*” choice to vary response patterns. Initial testing on non-participating volunteers with and without ASD confirmed clear preferences for phrase completion format for timing, content clarity, and ease of completion. Content adjustments generated by feedback were retested.

The questionnaire included the option to provide free text feedback on healthcare issues and/or the questionnaire so that appropriate content and format adjustments could be made in further instrument development.

3. Results

All statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS; version 21). Inspections of raw data, case processing summaries, and frequency distributions revealed no systematic missing data or concerning outliers. The influences of outliers were individually determined to contribute to more conservative results, and were therefore retained. Positive skew for some distributions indicated floor effects that reflected low levels of challenges for women without ASD. In contrast, the reverse ceiling effect pattern for some distributions resulted in negative skew due to high levels of challenge in the ASD group. This might be expected for small sample sizes using unidimensional scales. Tests of normality were checked via Kolmogorov-Smirnov tests, with Shapiro-Wilks statistics confirming

expected non-normality. Stratified bootstrapping was applied to statistical analyses to address issues of non-normality of distributions.

Homogeneity of variance was confirmed via non-significant Levene's test statistics for all items except general healthcare item 7, $F(1, 55) = 5.61, p = .02$; and the second maternity item for managing extra appointments, $F(1, 39) = 7.15, p = .01$. In order to address these breaches of homogeneity the analyses for these two items were conducted via bootstrapped independent samples t -test (2-tailed) using the significance (p) value for "equal variances not assumed". The effect size for item 7 was calculated as Cohen's d . All other tests for items without breaches of homogeneity were conducted via univariate tests of between-subject effects in order to obtain partial eta squared measures of effect size. This method is considered equivalent to 2-tailed independent samples t -tests when comparing only two groups whereby equal variances are assumed.

The two groups of women (high functioning ASD and non-ASD) were compared on the general health care items using an adjusted family-wise alpha level of .003. Maternity items were compared using an adjusted family-wise alpha level of .01. These error level adjustments were made owing to the exploratory nature of the study using a newly developed questionnaire.

3.1 General healthcare communication

Results showed that when compared with other women, high functioning ASD women experienced significantly more anxiety during health care appointments and in waiting rooms due to the presence of others. Further, once distressed within health care settings, high functioning ASD women also experienced significantly greater reductions in their capacity to communicate verbally. Descriptive data, statistical significance, and effect sizes are shown in Table 2.

Table 2.
Perceptions of General Healthcare Experiences

Item	Non-ASD (N = 26) Mean (SD) [95% CI]	ASD (N = 32) Mean (SD) [95% CI]	<i>p</i> -value	95% CI MD	Effect Size η_p^2
1. When communicating verbally with healthcare professionals I experience no...continual frustration or misunderstandings	4.00 (3.30) [2.76, 5.28]	6.03 (2.87) [4.97, 7.00]	0.02	[-3.51, -0.33]	0.10
2. Healthcare appointments never...always make me anxious	4.46 (3.22) [3.31, 5.65]	6.94 (2.93) [5.91, 7.81]	0.003*	[-3.88, -0.95]	0.14
3. When I am asked to verbally describe physical symptoms I am never...always confident I will be understood [†]	5.88 [†] (2.99) [4.72, 7.00]	3.75 [†] (2.66) [2.88, 4.69]	0.006	[0.66, 3.51]	0.13
4. When I am asked to verbally describe pain I never...always have difficulty	4.35 (3.35) [3.15, 5.58]	5.44 (2.77) [4.47, 6.38]	0.18	[-2.65, 0.51]	0.03
5. When healthcare professionals ask me detailed questions or give me lengthy verbal instructions in a consultation I never...always experience confusion	4.08 (3.10) [2.96, 5.32]	6.31 (2.71) [5.34, 7.22]	0.005	[-3.67, -0.75]	0.13
6. With respect to the range of different healthcare services I never...always avoid or dislike particular services	3.92 (3.29) [2.73, 5.23]	6.22 (3.34) [5.03, 7.34]	0.01	[-3.92, -0.55]	0.11
7. When I experience recurrent symptoms or problems that may be intermittent, such as occasional pain, my decision and efforts to seek diagnostic healthcare appointments are never...always delayed	5.60 (3.28) [4.28, 6.88]	7.25 (2.29) [6.41, 8.03]	0.04	[-3.09, -0.10]	<i>d</i> =.58
8. When I am emotional or distressed in a healthcare consultation or setting, my verbal communication skills are never...always reduced	4.92 (3.17) [3.69, 6.23]	7.72 (2.32) [6.88, 8.50]	<0.001*	[-4.23, -1.24]	0.21
9. Sensory experiences within health consultations never...always make me anxious	3.77 (3.42) [2.50, 5.23]	6.38 (3.27) [5.25, 7.50]	0.005	[-4.28, -0.81]	0.14
10. Sensory experiences in healthcare waiting rooms never...always make me anxious	3.84 (3.48) [2.60, 5.32]	6.00 (3.01) [4.91, 7.03]	0.02	[-3.84, -0.38]	0.10
11. The presence of other patients in healthcare service waiting rooms never...always makes me anxious	3.35 (3.21) [2.08, 4.58]	5.97 (3.18) [4.91, 7.06]	0.003*	[-4.32, -0.93]	0.15
12. I find that lengthy instructions, such as when to fill prescriptions, have tests, and make follow-up appointments, are never...always easily understood or recalled	5.77 (3.15) [4.54, 6.96]	3.84 (3.01) [2.91, 4.94]	0.02	[0.36, 3.44]	0.09
13. It is likely that written communication in health consultations, such as checklists, symptom journals, and medical instructions, would never...always be something that I would use	5.23 (3.30) [3.96, 6.46]	6.94 (2.55) [6.03, 7.72]	0.03	[-3.26, -0.16]	0.08

14. When I experience pain, injury, or discomfort I am never...always aware of it [†]	7.36 [†] (2.53) [6.28, 8.36]	6.84 [†] (2.68) [5.97, 7.72]	0.46	[-0.91, 1.86]	0.01
15. With regard to adhering to post-appointment self-healthcare and instructions (such as wound care or medications) I manage to never...always follow instructions exactly [†]	7.15 [†] (2.20) [6.31, 7.85]	6.81 [†] (2.49) [5.94, 7.63]	0.59	[-0.89, 1.51]	0.01
16. With reference to my overall self-reliance in healthcare, I am never...always confident that I cope [†]	7.08 [†] (2.80) [5.89, 8.04]	6.13 [†] (2.55) [5.22, 7.03]	0.18	[-0.56, 2.26]	0.03

Note. ASD = autism spectrum disorder; * Significant at $p \leq 0.003$; CIs based on 1000 stratified bootstrap samples; MD = Difference between Means; † = Lower scores on these items represent greater challenges

3.2 Maternity healthcare communication

Two of the five maternity items revealed statistically significant between group differences, being information and support during pregnancy and communication of pain and needs during childbirth. Autistic status accounted for 20% of the variation in scores for information and support during pregnancy, which women without ASD found more appropriate for their needs ($\eta_p^2 = .196$). Autistic status accounted for one quarter ($\eta_p^2 = .251$) of the variation in scores for communication of pain and needs during childbirth, which was significantly more problematic for women with ASD. Table 3 shows descriptive data for maternity experiences.

Table 3.
Maternity Healthcare Experiences

Item	Non-ASD (N = 19) Mean (SD) [95% CI]	ASD (N = 22) Mean (SD) [95% CI]	<i>p</i> -value	95% CI MD
Information and support services for pregnancy were never...always appropriate for my needs [†]	6.26 [†] (2.33) [5.14, 7.39]	3.95 [†] (2.44) [2.87, 5.04]	0.004*	[0.84, 3.71]
Managing the extra medical appointments and procedures required during pregnancy was never...always a problem	4.32 (3.53) [2.62, 6.02]	5.95 (2.55) [4.82, 7.09]	0.10	[-3.43, 0.35]
Information and support services during childbirth were never...always appropriate for my needs [†]	5.47 [†] (2.91) [4.07, 6.88]	4.33 [†] (2.60) [3.15, 5.51]	0.20	[-0.70, 2.84]
Communication of my pain, concerns, and/or needs during childbirth was never...always a problem	3.89 (2.60) [2.64, 5.15]	6.73 (2.41) [5.66, 7.80]	0.001*	[-4.34, -1.28]
Information and support services for breastfeeding my child is/was never...always appropriate [†]	5.47 [†] (2.89) [4.08, 6.87]	4.14 [†] (2.61) [2.98, 5.29]	0.13	[-0.37, 3.05]

Note. ASD = autism spectrum disorder; * Significant at $p \leq 0.01$; CIs based on 1000 stratified bootstrap samples; MD = Difference between Means; [†] = Lower scores on these items represent greater challenges.

3.3 ASD stigma and disclosure

Descriptive data for scale items measuring perceptions relating to diagnostic disclosure by women with high functioning ASD are shown in Table 4. Fifteen (75%) respondents reported “true” to the additional True/False item, “*I have not disclosed being on the Autism spectrum at least once because I felt that disclosure would affect treatment or communication*”.

Table 4.
Diagnostic Disclosure of High Functioning ASD – Scale Items

Item	N = 20 Mean (SD)	Never/ Infrequently	Scale Midpoint	Always/ Frequently
When I disclose being on the Autism spectrum to healthcare professionals they never...always respond negatively	7.0 (2.18)	3 (15%)	2 (10%)	15 (75%)
When I disclose being on the Autism spectrum, I feel that this never...always influences diagnosis or treatment	5.4 (3.14)	7 (35%)	3 (15%)	10 (50%)
Healthcare professionals with limited or inaccurate knowledge of Autism spectrum conditions never...always frustrate me	9.5 (1.15)	0	0	20 (100%)
Healthcare information relating specifically to my needs as a woman (e.g. menopause) on the Autism spectrum would be never...always useful	6.7 (2.70)	3 (15%)	5 (25%)	12 (60%)
When I disclose being on the Autism spectrum to healthcare professionals they never...always respond positively*†	2.95† (1.28)	13 (68.4%)	6 (31.6%)	0
When I do not disclose that I have an Autism spectrum condition, I generally feel that the treatment I receive from health professionals is never...always a problem	5.05 (2.42)	6 (30%)	6 (30%)	8 (40%)

Note. ASD = autism spectrum disorder; * N = 19 for this item; † = Lower scores on this item represent greater challenges.

4. Discussion

The results partially support the hypothesis that women with high functioning ASD experience greater healthcare challenges compared to women without ASD. Statistically significant differences were found for healthcare anxiety, communication under emotional distress, anxiety related to the presence of other patients in waiting rooms, support during pregnancy, and communication of pain and needs during childbirth. In all cases, women with ASD were more likely to perceive

difficulties/dissatisfaction than the women without ASD. The two groups were very similar on other measures.

The experience of significantly higher anxiety in waiting rooms when other patients were present (compared to the experience of other women in the same context) may reflect social-sensory events brought on by the presence of others, such as loud talking, crying children, medication and perfume odours in addition to anxiety related to interpersonal communication. Environmental, social, and stigma stressors prior to consultations may contribute to emotional regulation challenges for individuals with ASD (Bölte, et al., 2008; Laurent & Rubin, 2004; Samson, et al., 2012).

Significantly higher challenges communicating pain, concerns, and/or needs during childbirth for women with ASD, compared to women without ASD, may reflect the influence of emotional, sensory, and physical distress during labour and delivery. Women with ASD also reported less endorsement of the utility of information and support received during pregnancy. These areas should be addressed by future research. Further, both groups gave very neutral scores on the obstetrics measures, including information and support for childbirth and breast-feeding. These results suggest the need for increased resources to support all women in maternity settings.

The data for disclosure of autistic status indicated high levels of negative responses and 100% of participants had experienced frustration with uninformed clinicians. Non-disclosure by 75% of the sample is particularly concerning and training of clinicians about the specific needs and concerns of adults with high functioning ASD, combined with steps to encourage patients to disclose, may improve these rates and perceptions.

Voluntary disclosure of ASD status would enable specific accommodations in healthcare to reduce challenges. Disclosure could inform clinical reasoning relating to information gathering, including consideration of physiological conditions associated with ASD as raised by Bruder et al. (2012). Future research is therefore required to explore ASD stigma in healthcare settings. This could include, for example, whether clinician lack of awareness of characteristic ASD traits and behaviours influences clinical reasoning for patients who disclose as well as for patients who do not.

Improved clinician awareness of ASD and stigma may improve healthcare through minimizing potential problems such as diagnostic overshadowing, misdiagnosis, and service avoidance by patients. Understanding that women with ASD report significantly reduced communication under emotional distress, for example, could guide clinical adjustments with respect to information gathering, interpersonal interaction, and environmental stressors.

Clinician awareness should enable collaborative patient-practitioner determination of accommodations required to meet individual patient needs and reduce healthcare anxiety. Communication may be enhanced via use of written resources or visual pain scales, for example. Environmental accommodations might include appointments outside peak service times to reduce anxiety relating to the presence of other patients in waiting rooms. Additionally, patients might be supported to trial strategies such as personal headphones to reduce anxiety that may relate to waiting room noise caused by other patients and reduce the likelihood of interaction with other patients.

The questionnaire used was collaboratively designed to overcome some of the most important issues related to traditional questionnaires in studies of adults with high functioning ASD. Comparisons between women, who commonly act as an advocate for relatives and attend obstetrics settings, also allowed the study to make

some important contributions. Development of a reliable measure of healthcare experiences may be useful to identify and address practical challenges that impact quality of life and psychological wellbeing.

However, self-reporting by a small sample of convenience using an exploratory questionnaire limits generalisation. Larger random sampling would allow multivariate, factor, and reliability analyses. Although useful in guiding future research, this small pilot study sample was insufficient to meet participant to variable ratios required for factor extraction and internal consistency reliability testing.

The inclusion of reliable autistic trait measures as employed by Nicolaidis et al. (2013) could provide a means to overcome the limitations of self-reported diagnostic status as well as undiagnosed ASD in control groups. It would also enable analyses of covariance of autistic traits with healthcare variables. Difficulties with the perception and communication of pain could be explored through measures of body awareness.

Further, studies with larger population samples would benefit by including male participants to measure differences within and between genders. This should include perceptions of ASD stigma. Finally, the potential influence of age on healthcare challenges for individuals with ASD may also be required given healthcare implications for ageing populations.

5. Conclusions and Implications

This pilot study provides insight into healthcare challenges perceived by women with and without ASD. The challenges for high functioning women with ASD suggest complex interactions of their characteristic social, emotional, communication, sensory, and behavioural differences compared to women without ASD. Future research should explore these complex influences and perceived stigma in order to address potential healthcare and health disparities.

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