

Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study.

Mary Doherty¹, Jane D. O’Sullivan², Stuart D. Neilson³

1. Department of Anaesthesia
Our Lady's Hospital
Navan
Meath
Ireland
Corresponding author: drmdoherty@gmail.com
2. Department of Anaesthesia
Waterford Regional Hospital
Waterford
Ireland
3. Independent Researcher
Cork
Ireland

1. Abstract

Background: Autism is associated with reduced life expectancy, poor physical and mental health, and increased prevalence of epilepsy, obesity, hypertension, diabetes and stroke.
Aim: To quantify self-reported barriers to healthcare and their consequences amongst autistic adults and compare with parents of autistic children and non-autistic controls
Design and Setting: An online survey was developed from a qualitative study undertaken at Autscope, an autistic conference.
Method: Thematic analysis of 75 responses was used to develop a 57-item online survey completed by 1,271 autistic adults, 406 parents of autistic children and 303 control subjects.
Results: Difficulty visiting a GP was reported by 78.2% of autistic adults, 51.4% of parents and 34.9% of controls. The highest-rated barriers by autistic adults were deciding if symptoms warrant a GP visit (71.9%), difficulty using the telephone to book appointments (60.7%), not feeling understood (55.5%) and difficulty communicating with their doctor (53.0%). A higher rate of adverse health outcomes was reported by autistic adults; untreated physical and mental health conditions, not attending specialist referral or screening programmes, requiring more extensive treatment or surgery due to late presentations, and untreated potentially life threatening conditions. Autistic adults reported a need for online or text based appointment booking, facility to email in advance the reason for consultation, first or last clinic appointment and a quiet place to wait.
Conclusion: Reduction of healthcare inequalities for autistic people requires that healthcare providers understand autistic culture and communication needs. Adjustments for autistic communication needs are as necessary as ramps are for wheelchair users.

How this fits in: Autistic adults avoid seeking health care due to difficulty making appointments and not feeling understood, which may explain poor health outcomes and increased mortality.

1. Autism is a neurodevelopmental condition involving social communication challenges.
2. Autistic people have poor general health, reduced life expectancy with a mortality gap of 16 to 30 years, and even increased in-hospital mortality.
3. Reduced healthcare seeking behaviour results from communication challenges, primarily difficulties using the phone to make appointments, not feeling understood, and anxiety which decreases communication abilities.
4. Autistic people require reasonable adjustments and support to access healthcare in order to improve outcomes and reduce healthcare inequality.

2. Introduction

Autism is a common neurodevelopmental condition which affects 1-2% of the population [1] at all ages [2]. It is usually diagnosed in childhood, but improved awareness has led to increasing rates of adult diagnosis [3]. Autism is heterogeneous, with a wide range of presentations [4] and co-occurring conditions [5]. It presents challenges in social communication, atypical behaviour and sensory issues. Unusual or intense interests are

common, as are repetitive movements and behaviours, and a need for predictability and routine [6]. Executive functioning difficulties, while not included in the diagnostic criteria, occur frequently [7].

Autism is associated with premature mortality [8,9,10]. A large Swedish cohort study found that life expectancy was 16 years shorter for autistic adults without an intellectual disability and up to 30 years shorter for those with co-occurring intellectual disability, with increased mortality across almost all diagnostic categories [8]. Autistic adults have poorer physical and mental health [11] in comparison with the general population, with higher rates of most medical conditions [12]. Specifically, there is a notably greater prevalence of sleep disorders, epilepsy, food intolerance, gastrointestinal dysfunction, mood disorder and self-injurious behaviours [13], and high prevalence of diabetes mellitus, hypertension and obesity [14]. In-hospital mortality is increased [15] and autistic people are three times more likely to use emergency departments, to require inpatient admission, and to die after attending emergency care [16].

Autism has recently been designated a priority area for the NHS [17]. Progress in reducing the disparity in health outcomes for disabled and autistic people has been slow [18], although a number of avenues in GP training have been identified [19, 20] and formalised into specific awareness-raising interventions [21].

Previous studies have shown that barriers to healthcare access are multi-factorial [12, 22]. A recent systematic review noted particular challenges in the areas of communication, sensory issues and executive functioning [23]. Parents of autistic children also experience barriers to accessing healthcare [24]. The primary care experiences of parents have not previously been explored.

This is the first comparison of the experiences of autistic adults, parents of autistic children and adult controls. This study began as a community-based quality improvement survey which asked a large group of autistic adults “what do you wish your GP knew about autism?” and was then extended and administered to an online community. Our aim was to identify the nature and magnitude of the access barriers for autistic adults in comparison with parents of autistic children and with neurotypical adults, along with the self-reported consequences of failure to access healthcare. Only by understanding the healthcare experiences of the autistic community and addressing the specific access barriers identified will significant progress be made to reduce healthcare inequalities in this vulnerable group of patients.

3. Method

An initial pilot survey was conducted at Autscope 2018, a conference organised by and for autistic people [25]. The qualitative survey with 75 pilot participants concentrated on four key themes: the barriers faced in accessing GP care, what GPs need to know about autism, what works well, and what would make visits easier. The qualitative survey delineated three key issues: communication (most notably using the telephone), sensory issues (e.g. in crowded waiting areas), and executive functioning (most notably difficulty planning appointment in advance).

Thematic analysis was used to develop a 57-item survey to explore these issues in greater depth and delivered to a wider population via an online survey, with recruitment of autistic participants, parents of autistic children and non-autistic controls via autism conferences and social media. The online survey was completed by a total of 1,980 respondents: 1,271

(64.2%) autistic adults, 406 (20.5%) parents of autistic children and 303 (15.3%) control respondents. The mean ages of these three groups were comparable at 38.6, 41.9 and 39.7 years respectively. 807 (40.8%) respondents were from the UK, 616 (31.1%) from Ireland, 334 (16.9%) from North America and 223 (11.2%) from other countries worldwide.

The majority of respondents were female, 63.7% of autistic adults, 93.8% of parents and 85.0% of control respondents. However, there was a prominent expression of non-binary gender by almost a fifth of autistic adults — 17.6% as compared with just 1.1% of control respondents and none of the parents.

The majority (913, 75.1%) of the self-identified autistic adults had a formal diagnosis of autism, established by a psychiatrist (29.6%), clinical psychologist (47.8%) or multidisciplinary team (22.7%).

The items assessing barriers to accessibility were in the form of yes-no responses, or single-item selections from a list. Significance of between-group differences was assessed using a 2x2 or 2xk Chi-squared test comparing, firstly, the autistic adults with all control participants (the parents of autistic children, and the control group) and, secondly, comparing the parents and control participants. The first reflects the direct experience of accessibility reported directly by autistic people, while the second comparison may reflect structural issues with managing autism care reported indirectly by their families.

Preliminary analysis of interim data revealed a recurring theme of total non-engagement with healthcare providers, despite expressed healthcare needs. An additional response option was added to the survey to explore this phenomenon.

Ethical approval was obtained from SJH/TUH Research Ethics Committee, Tallaght University Hospital.

4. Results

Of the 1,271 autistic respondents, 985 (78.2%) reported difficulty in visiting a GP when they need to, in contrast to 51.4% of parents and 34.9% of control respondents (**Table 1**). The self-reported difficulty was significantly higher in both autistic ($\chi^2=230.37$, $p<0.001$) and parent respondents ($\chi^2=18.33$, $p<0.001$), indicating a congruence between the two groups signifying common structural barriers to accessing primary care with autism.

When asked to identify individual barriers, autistic respondents identified every element other than “Not having enough time to visit the doctor” significantly more frequently than parents and controls (**Table 2**). The highest-rated barriers were “Difficulty deciding if symptoms warrant a GP visit” (71.9%, $\chi^2=83.27$, $p<0.001$), “Difficulty using the telephone to book appointment” (60.7%, $\chi^2=511.30$, $p<0.001$), “Not feeling understood” (55.5%, $\chi^2=321.04$, $p<0.001$) and “Difficulty communicating with the doctor during the appointment” (53.0%, $\chi^2=418.38$, $p<0.001$). Pain awareness and tactile sensitivity imposed further barriers. 55.5% of autistic people report that they are unable to describe their pain symptoms accurately, in contrast to 20.1% of control respondents and 13.3% of parents of autistic children ($\chi^2=287.33$, $p<0.001$). 35.1% of autistic people report that unexpected touch makes it difficult to visit the doctor, in contrast with 5.9% of control respondents and 6.9% of parents of autistic children ($\chi^2=197.86$ ($p<0.001$)).

74.3% of autistic adults reported that anxiety increases communication difficulty, significantly more than parents (23.2%) or control respondents (25.7%).

Parents identified five barriers significantly more often than controls, all congruent with the autistic adult respondents and indicative of structural barriers to autism care in primary practice. These were “Not having anyone to look after my child” ($\chi^2=68.43$, $p<0.001$), “Difficulty deciding if symptoms warrant a GP visit” ($\chi^2=31.48$, $p<0.001$), “The waiting room environment” ($\chi^2=10.91$, $p=0.001$), “Waiting to see the doctor is too difficult” ($\chi^2=7.13$, $p=0.008$) and “Difficulty using the telephone to book appointment” ($\chi^2=4.01$, $p=0.045$). Verbal communication issues are experienced by the autistic adults, most notably using the telephone, whereas the waiting environment is difficult for both autistic adults and parents with their autistic children.

When asked “What communication methods do you AVOID if possible?”, 78.1% of autistic respondents avoided the telephone, 61.1% voicemail and 29.7% face-to-face verbal communication, all significantly more frequently than parents or control respondents ($\chi^2=430.47$, 157.69 and 93.63 respectively, $p<0.001$). Parents also avoided face-to-face verbal ($\chi^2=12.90$, $p<0.001$) and voicemail communication ($\chi^2=10.42$, $p<0.001$) more often than control respondents (**Figure 1**).

Autistic adults more frequently experience a wide range of additional factors affecting their ability to access GP care (**Table 1**), including frequently or always having difficulty communicating (57.7%), physical mobility needs (15.8%) and non-binary gender identification (17.6%). A consistent theme was a lack of social networks to support health care access - autistic people had nobody available to support unexpected hospital admission (15.1%), collection from hospital (17.7%), home care following discharge (24.9%) and care for children when unwell (5.8%).

17.4% of autistic adults had not informed their doctor and 21.4% did not know if their doctor was aware of their diagnosis. In contrast, only 2.4% of parents had not informed their doctor and 8.6% did not know if their doctor was aware of their child’s diagnosis.

Autistic people reported a variety of adverse treatment consequences substantially and significantly more frequently than parents or control respondents (**Figure 2**). Autistic people reported their “Mental health condition remain untreated” 3.5 times more often ($\chi^2=481.70$, $p<0.001$), “Physical health condition remain untreated” 2.6 times more often ($\chi^2=256.26$, $p<0.001$), “Did not attend referral to a specialist” 2.1 times more often ($\chi^2=93.44$, $p<0.001$), “Told you should have seen a doctor sooner” 1.8 times more often ($\chi^2=59.03$, $p<0.001$), “More extensive treatment or surgery” 2.4 times more often ($\chi^2=67.60$, $p<0.001$), “Potentially serious or life threatening condition untreated” 4.1 times more often ($\chi^2=115.86$, $p<0.001$), and “Do not attend on schedule for screening programmes” 2.0 times more often ($\chi^2=167.19$, $p<0.001$). In all cases, autistic people reported these adverse treatment consequences more often than parents of autistic children, from 1.2 to 2.5 times more often, significantly for mental health care, being told they should have seen a doctor sooner and untreated life-threatening conditions.

In terms of suggestions for improving access, autistic adults reported (**Table 3**) that visiting their doctor would be easier if they could book an appointment online (68.6%, $\chi^2=16.2$), could book an appointment by text (37.1%, $\chi^2=28.62$), could book the first or last appointment of the day (40.4%, $\chi^2=11.00$), could wait in a quiet place or outside until it was their turn (54.5%, $\chi^2=213.21$) and could email their doctor in advance with a description of the issue they need to discuss (61.1%, $\chi^2=235.15$), in all cases significantly more often than parents or control respondents ($p<0.001$). Parents agreed that visiting a doctor would be easier if they could book an appointment online (56.2%, $\chi^2=4.14$, $p=0.042$), could book the first or last appointment of the day (38.4%, $\chi^2=13.43$, $p<0.001$) and could wait in a quiet place or outside until it was their child’s turn (28.6%, $\chi^2=35.86$, $p<0.001$). Both autistic adults

(40.8%, $\chi^2=159.85$, $p<0.001$) and parents (20.9%, $\chi^2=47.15$, $p<0.001$) were far more likely than control respondents (3.0%) to disagree or strongly disagree that their doctor was knowledgeable about autism.

A total of 25 autistic adults (4.93%), 5 parents of autistic children (2.55%) and 8 control respondents (5.0%) did not attend any doctor or medical practice. Within these non-attenders, 95.8% of autistic adults and 100.0% of parents had "difficulty visiting your doctor when you need to", as opposed to 57.1% of control respondents ($\chi^2=8.94$, $p=0.011$). 19 autistic non-attenders (76%), 2 parents (25%) and 2 controls (40%) reported telephone as the most difficult barrier and had "difficulty visiting your doctor when you need to", as opposed to 57.1% of control respondents ($\chi^2=5.55$, $p=0.018$).

In addition 76.0% of non-attending autistic adults and 60.0% of parents had a mental health condition remain untreated, as opposed to 37.5% of control respondents ($\chi^2=10.94$, $p=0.027$), and 100% of non-attending autistic adults and 80.0% of parents had at least one delayed treatment outcome, as opposed to 62.5% of control respondents ($\chi^2=9.60$, $p=0.082$).

5. Discussion

Summary

Autistic people experience barriers in accessing and engaging with primary healthcare. The self-reported barriers included greater difficulties deciding when to seek care, not wanting to bother their GP and, most significantly, greater communication difficulties. These barriers were most apparent in reliance on telephone contact. Autistic help-seeking occurs much further along the natural course of an illness, with self-reported reduced attendance for screening, late presentations, missed opportunities for early detection and more extensive therapy being required.

Parents of autistic children report some of the same experiences, for instance the waiting room environment activating sensory defensiveness. Parents focused on their child, possibly to the detriment of their own health, which was also impacted by difficulty with childcare. The self-reported barriers for parents of autistic children lay in between those reported by autistic and control respondents. This possibly indicates some level of undiagnosed autism among the parent group. There was a contrast between disclosure of children's autism by parents and self-disclosure by autistic adults, indicating a need for education of autistic young people and adults regarding healthcare and healthcare seeking behaviour.

The primary barrier experienced by autistic people in this study is communication, and the telephone in particular is a distilled, concentrated essence of verbal communication. These barriers represent not so much a failure to deliver or to avail of healthcare, but a lack of intersection between the communication patterns of autistic healthcare users and non-autistic providers, a phenomenon known as the double empathy problem [26]. Communication is impaired by anxiety, sensory issues and planning difficulties with regard to appointments. Autistic people delay or avoid healthcare because they do not feel understood by their doctors.

Autistic people report a diverse range of complicating factors, including a higher level of concurrent physical and mental health conditions, physical mobility needs, a restricted social support network and a high rate of non-binary gender identification.

This study examines the self-reported experience of healthcare barriers, identifying one process that appears to directly affect health outcomes for autistic people. These barriers have

real consequences, as evidenced in reduced life expectancy, and higher levels of physical and mental health conditions amongst autistic people.

Strengths and limitations

The survey was developed by an autistic-led research team from an initial community-based quality improvement project, which asked open questions of autistic adults attending Autscope 2018. This led to a unique picture of the healthcare experiences of autistic adults, in particular capturing those entirely excluded from healthcare due to access barriers.

This study differs from prior studies in selecting a community-based sample. Previous studies included participants who engage with existing medical services and were limited by failing to capture participants who do not engage with medical services.

The online survey did not directly interrogate this issue until preliminary analysis of interim qualitative data identified an unexpected level of involuntary total disengagement with medical services. The significant difficulties amongst the small group of non-attenders included in this study indicate an urgent need for further research into autistic people not registered with any GP. This may explain the increased use of emergency departments and poorer outcomes following such presentations, including higher rates of admission and mortality.

This is the first comparison of the healthcare experiences of autistic adults, parents of autistic children and adult controls. This survey did not collect data on health outcomes for parents of autistic children, which is an area for further study.

Comparison with existing literature

Recent initiatives to improve healthcare access, such as annual health checks [18], will be ineffective if the barriers outlined here are not addressed. Specific training for general practitioners is required [19,20], and this should be developed and delivered by autistic healthcare professionals where possible. Greater autism awareness among GPs exists where they have personal knowledge of autism, whether through having a relative or friend on the autistic spectrum, or being autistic themselves [20]. GPs with a special interest in autism should be facilitated to develop their skills, but management of general health needs and co-occurring conditions should be within the remit of every GP [21]. In the general population, social health care interventions have been demonstrated to reduce the rate of unplanned hospital admissions, and, ultimately, healthcare-associated costs. [27]. Such social interventions may be amenable to adaptation for the autistic population in order to facilitate access to primary healthcare.

Implications for policy and practice

Reduction of healthcare access barriers for autistic people is urgently required. The success of initiatives such as annual health checks will be dependent on greater awareness by medical practitioners of autistic culture and communication needs. Reasonable accommodations are legally and morally required, and adjustments for communication needs are as necessary for autistic people as ramps are for wheelchair users.

A checklist for accessibility is required in autism aware and autism friendly healthcare settings. These adjustments would maximise the consultation efficacy by minimising anxiety and stress during waiting time, managing sensory issues, and ensuring mutual understanding with clear, unambiguous communication. Autism friendly practices should employ a personalised approach, with a healthcare access needs assessment and, where possible, the availability of a specialist practice nurse. Designation of general practice surgeries as autism

friendly involves autism awareness training for medical and support staff, the availability of a range of non-telephone based booking and communication modes and attention to sensory issues in the environment.

Continuity of care is a core principal of primary care, and low continuity of care is associated with higher mortality [28] yet if a large number of autistic adults find healthcare inaccessible then general practice is failing this vulnerable group of patients in terms of its primary aim. If autistic people are failing to seek healthcare for life threatening conditions, then it is axiomatic that this would increase mortality. When over half of our patients do not present for care when needed because they don't feel understood, we as doctors are failing in our duty to these patients. We need to make primary care safe and accessible for the autistic community by addressing the access barriers identified in this study.

Acknowledgements

We thank Dr David Hillebrandt, Professor Louise Gallagher and Karen Leneh Buckle for their assistance during this project. We are grateful to AsIAM, Ireland's National Autism Charity and Scally's SuperValu, Clonakilty, for the funding to enable open access publication.

6. References

1. CDC. Data and Statistics. Autism Spectrum Disorder. Resource Document. [Last accessed on 2016 Jul 03]. Available from: <http://www.cdc.gov/ncbddd/autism/data.html>
2. Brugha TS, McManus S, Bankart J, et al. Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry*. 2011 May 2;68(5):459-65.
3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*. 2015 Nov;2(11):1013–27.
4. Witwer AN, Lecavalier L. Examining the Validity of Autism Spectrum Disorder Subtypes. *J Autism Dev Disord*. 2008 Oct;38(9):1611–24.
5. Gillberg and C, Billstedt E. Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatr Scand*. 2000 Nov;102(5):321–30.
6. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Washington, D.C.: American Psychiatric Association; 2013 May 22.
7. Corbett BA, Constantine LJ, Hendren R, et al. Examining executive functioning in children with autism spectrum disorder, attention deficit hyperactivity disorder and typical development. *Psychiatry Res*. 2009 Apr;166(2–3):210–22.
8. Hirvikoski T, Mittendorfer-Rutz E, Boman M, et al. Premature mortality in autism spectrum disorder. *Br J Psychiatry*. 2016 Mar;208(3):232–8.

9. Hwang YI, Srasuebkul P, Foley KR, et al. Mortality and cause of death of Australians on the autism spectrum. *Autism Res.* 2019 May;12(5):806-15.
10. Bilder D, Botts EL, Smith KR, et al. Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. *Journal Autism Dev Disord.* 2013 May 1;43(5):1196-204.
11. Rydzewska E, Hughes-McCormack LA, Gillberg C, et al. General health of adults with autism spectrum disorders—A whole country population cross-sectional study. *Res Autism Spectr Disord.* 2019 Apr 1;60:59-66.
12. Croen LA, Zerbo O, Qian Y, et al. The health status of adults on the autism spectrum. *Autism.* 2015 Oct;19(7):814–23.
13. Xue Ming, Brimacombe M, Chaaban J, et al. Autism Spectrum Disorders: Concurrent Clinical Disorders. *J Child Neurol.* 2008 Jan;23(1):6–13.
14. Flygare Wallen E, Ljunggren G, Carlsson AC, et al. High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. *J Intellect Disabil Res.* 2018 Apr;62(4):269-80.
15. Akobirshoev I, Mitra M, Dembo R, et al. In-hospital mortality among adults with autism spectrum disorder in the United States: A retrospective analysis of US hospital discharge data. *Autism.* 2019 Jun 12:1362361319855795.
16. Vohra R, Madhavan S, Sambamoorthi U. Emergency department use among adults with autism spectrum disorders (ASD). *J Autism Dev Disord.* 2016 Apr 1;46(4):1441-54.
17. NICE. Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Leicester (UK): British Psychological Society; 2012.
18. Lennox N, Van Driel ML, van Dooren K. Supporting primary healthcare professionals to care for people with intellectual disability: a research agenda. *J Appl Res Intellect Disabil.* 2015 Jan;28(1):33-42.
19. Zerbo O, Massolo ML, Qian Y, et al. A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *J Autism Dev Disord.* 2015 Dec;45(12):4002–14.
20. Unigwe S, Buckley C, Crane L, et al. GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *Br J Gen Pract.* 2017 Jun;67(659):e445–52.
21. Buckley C. Making your practice autism friendly. *InnovAiT.* 2017 Jun;10(6):327-31.
22. Raymaker DM, McDonald KE, Ashkenazy E, et al. Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism.* 2017 Nov;21(8):972–84.

23. Mason D, Ingham B, Urbanowicz A, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord*. 2019 May 23:1-4.
24. Chiri G, Warfield ME. Unmet Need and Problems Accessing Core Health Care Services for Children with Autism Spectrum Disorder. *Matern Child Health J*. 2012 Jul;16(5):1081–91.
25. The Autscope Organisation. Autscope 2018: Exploring Inclusion. Tonbridge, Kent: 2018. Available from: <http://www.autscope.org/2018/>
26. Milton DE. On the ontological status of autism: the ‘double empathy problem’. *Disability & Society*. 2012 Oct 1;27(6):883-7.
27. Abel J, Kingston H, Scally A, et al. Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities. *Br J Gen Pract*. 2018 Nov;68(676):e803–10.
28. Maarsingh OR, Henry Y, van de Ven PM, et al. Continuity of care in primary care and association with survival in older people: a 17-year prospective cohort study. *Br J Gen Pract*. 2016 Aug 1;66(649):e531-9.

Table 1

Healthcare needs and barriers

	Autistic	Control	Parents	Autistic vs. Other, χ^2 (p)	Parent vs. Control, χ^2 (p)
Difficulty visiting doctor	985 (78.2%)	105 (34.9%)	208 (51.4%)	230.37 (p<0.001)	18.33 (p<0.001)
Frequently or always have difficulty communicating	731 (57.7%)	33 (10.9%)	52 (12.9%)	733.80 (p<0.001)	8.08 (p=0.152)
Mobility needs	199 (15.8%)	13 (4.3%)	21 (5.2%)	50.78 (p<0.001)	0.13 (p=0.718)
Non-binary gender identification	223 (17.6%)	8 (2.7%)	0 (0.0%)	186.37 (p<0.001)	24.50 (p<0.001)
Nobody would be available to...					
Bring your personal belongings to you in hospital	192 (15.1%)	13 (4.3%)	26 (6.4%)	39.82 (p<0.001)	1.11 (p=0.292)
Collect you after a hospital day case surgical procedure	225 (17.7%)	12 (4.0%)	25 (6.2%)	60.70 (p<0.001)	1.28 (p=0.258)
Assist you at home after an operation	316 (24.9%)	25 (8.3%)	67 (16.5%)	38.58 (p<0.001)	9.74 (p=0.002)
Care for your child if you were unable due to illness	74 (5.8%)	10 (3.3%)	56 (13.8%)	7.90 (p=0.005)	21.4 (p<0.001)

Table 2

Which of the following would cause you to delay or avoid seeing your doctor when you need to?

	Autistic	Control	Parents	Autistic vs. Other, χ^2 (p)	Parent vs. Control, χ^2 (p)
Difficulty deciding if symptoms warrant a GP visit	914 (71.9%)	193 (63.7%)	171 (42.1%)	83.27 (p<0.001)	31.48 (p<0.001)
Difficulty using the telephone to book appointment	772 (60.7%)	33 (10.9%)	26 (6.4%)	511.30 (p<0.001)	4.01 (p=0.045)
No online booking system	461 (36.3%)	63 (20.8%)	79 (19.5%)	55.93 (p<0.001)	0.12 (p=0.731)
There is an online booking system but it's confusing	220 (17.3%)	15 (5.0%)	12 (3.0%)	74.75 (p<0.001)	1.38 (p=0.240)
Difficulty planning an appointment in advance	583 (45.9%)	87 (28.7%)	104 (25.6%)	67.70 (p<0.001)	0.70 (p=0.404)
Difficulty communicating with the reception staff	514 (40.4%)	25 (8.3%)	27 (6.7%)	242.73 (p<0.001)	0.44 (p=0.507)
Difficulty communicating with the doctor during the appointment	674 (53.0%)	21 (6.9%)	27 (6.7%)	418.38 (p<0.001)	0.00 (p=1.000)
The waiting room environment	599 (47.1%)	26 (8.6%)	71 (17.5%)	221.89 (p<0.001)	10.91 (p=0.001)
Inability to see a known or preferred doctor	527 (41.5%)	72 (23.8%)	88 (21.7%)	70.89 (p<0.001)	0.32 (p=0.571)
Long wait to get an appointment	592 (46.6%)	122 (40.3%)	155 (38.2%)	10.12 (p=0.001)	0.24 (p=0.627)
Waiting to see the doctor is too difficult	253 (19.9%)	15 (5.0%)	44 (10.8%)	45.14 (p<0.001)	7.13 (p=0.008)
Not feeling understood	705 (55.5%)	43 (14.2%)	57 (14.0%)	321.04 (p<0.001)	0.00 (p=1.000)
Not having enough time to visit the doctor	426 (33.5%)	106 (35.0%)	122 (30.0%)	0.32 (p=0.571)	1.72 (p=0.190)
Needing a support person to come with me	284 (22.3%)	10 (3.3%)	22 (5.4%)	106.56 (p<0.001)	1.35 (p=0.246)
Not having anyone to look after my child	159 (12.5%)	29 (9.6%)	151 (37.2%)	52.29 (p<0.001)	68.43 (p<0.001)
None of the above	24 (1.9%)	33 (10.9%)	47 (11.6%)	78.85 (p<0.001)	0.03 (p=0.869)

Table 3

Visits to my doctor would be easier if...

	Autistic	Control	Parents	Autistic vs. Other, χ^2 (p)	Parent vs. Control, χ^2 (p)
I could book an appointment online	872 (68.6%)	194 (64.0%)	228 (56.2%)	16.20 (p<0.001)	4.14 (p=0.042)
I could book an appointment by text	472 (37.1%)	73 (24.1%)	106 (26.1%)	28.62 (p<0.001)	0.27 (p=0.600)
I could book the first or last appointment of the day	513 (40.4%)	76 (25.1%)	156 (38.4%)	11.00 (p=0.001)	13.43 (p<0.001)
I could wait in a quiet place or outside until it was my turn	693 (54.5%)	30 (9.9%)	116 (28.6%)	213.21 (p<0.001)	35.86 (p<0.001)
I could email my doctor in advance with a description of the issue I need to discuss	777 (61.1%)	73 (24.1%)	105 (25.9%)	235.15 (p<0.001)	0.20 (p=0.653)
None of the above	45 (3.5%)	64 (21.1%)	68 (16.7%)	125.25 (p<0.001)	1.91 (p=0.167)

Figure 1

What communication methods do you AVOID if possible?

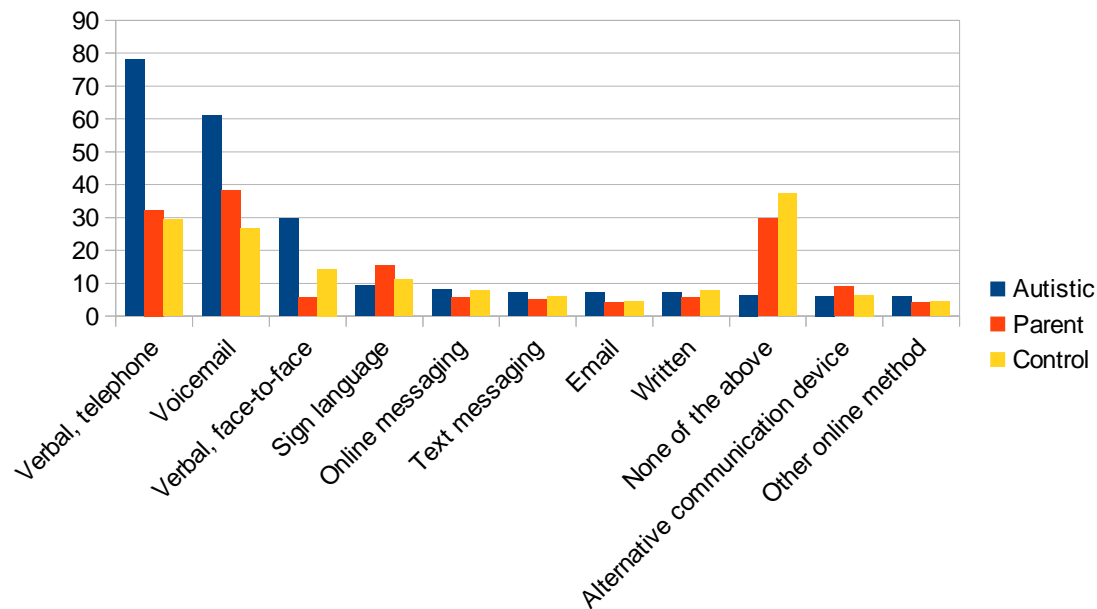


Figure 2

Adverse outcomes in delayed and additional healthcare treatment

