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TITLE: How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians

ABSTRACT

Autism Spectrum Condition (ASC) is associated with co-occurring physical health conditions and premature mortality. Autistic people experience multiple barriers to accessing healthcare. This study investigated autistic people's experiences of healthcare, and professionals' experiences of providing healthcare to autistic people. Focus groups with 11 autistic people and one supporter, and 15 one-to-one interviews with healthcare professionals were completed. Nine themes emerged from the autistic participants' data and eight themes emerged from the health professionals' data. Three themes were identified by both groups: healthcare contacts (for improving the patient-provider relationship), making reasonable adjustments to healthcare (for example, providing alternative places to wait for an appointment), and autism diagnosis. Autistic participants discussed the role of cognitive factors in the success of healthcare visits (such as rehearsing an anticipated conversation with the clinician the night before an appointment) and clinicians described system-level constraints that may affect healthcare delivery (such as time limits on appointments). This study identified inexpensive changes that health professionals and managers can make to improve healthcare access for autistic people.

LAY SUMMARY

Research has shown that on average, autistic people are more likely to die earlier than non-autistic people, and barriers can stop autistic people accessing healthcare. We carried out a study where we interviewed healthcare professionals (including doctors and nurses), and held discussion groups of autistic people. Our results highlighted several key points: seeing the same professional is important for autistic people and clinicians; both clinicians and autistic people think making adjustments to healthcare is important (and often possible); autistic people process information in a different way and so may need extra support in appointments; and that clinicians are often constrained by time pressures or targets.

INTRODUCTION

Autism Spectrum Conditions (ASC) are associated with an increased prevalence of multiple psychological and physical health conditions and premature mortality. A recent meta-analysis reported estimated lifetime depression and anxiety to be 37% and 42% respectively (Hollocks et al. 2019); which is consistent with the results of a recent study of medical records (Croen et al. 2015). However, the physical health of autistic people has been overlooked in research. The literature to date indicates autistic people have poorer health outcomes, compared to comparison samples. Hirvikoski et al. (2016) reported that compared to a general population sample (matched on gender, year of birth, and country of residence, none of whom were diagnosed with autism), having an ASC diagnosis was associated with increased mortality across all ICD-10 diagnostic categories included in their study, besides infections (e.g. endocrine, mental/ behavioural disorder, nervous system, digestive system, and death by suicide). Further, autistic people died on average approximately 17 years earlier than those people in the comparator group (approximately 30 years earlier for autistic people with a co-occurring intellectual disability, and approximately 12 years earlier for autistic

people without a co-occurring intellectual disability) (Hirvikoski et al. 2016). Regarding physical health diagnoses, one large study reported, using age and gender matched control groups, greater prevalence of multiple physical health conditions including cardiovascular disease (odds ratio, OR, 2.54); diabetes (OR 2.18); neurologic diseases (e.g. epilepsy, cerebral palsy, Parkinson's disease; OR 2.12) (Croen et al. 2015). More contemporary research has suggested that the prevalence of health conditions is greater in older, compared to younger, autistic people (Bishop-Fitzpatrick and Rubenstein 2019).

Cashin et al. (2018) have highlighted the importance of considering the health of autistic people across the lifespan. They suggest that because there is elevated risk of chronic disease occurring early in childhood, the risk of poor outcomes in adulthood and older age is increased. However, focusing solely on the autistic individual may not fully explain these poorer health outcomes. Autistic people also face healthcare disparities based on race, socioeconomic status, and age, and there is a little research on how these factors impact on physical healthcare outcomes (Bishop-Fitzpatrick and Kind 2017). These disparities are important to address given autistic people are more likely to have contact with health services (for example, general practitioners; Foley et al. 2018, or emergency departments; Vohra et al. 2016). Taken together, these results suggest interventions and strategies are required to improve the physical health of autistic people. The aim of this study was to contribute to the physical health care and autism literature by comparing perspectives on the healthcare experiences of autistic people, and the experiences of clinicians providing healthcare to autistic people.

One such factor that may impact health outcomes is difficulty accessing healthcare. A recent conceptual framework identified three domains of barriers to healthcare access as reported by autistic people; patient-level, provider-level, and system level barriers (Nicolaidis et al. 2015). Patient-level barriers include verbal communication skills, sensory sensitivities, and problems describing physical sensations and internal states. This latter feature may be related to alexithymia; a construct defined as a difficulty describing and/or feelings, and an externally orientated thinking style (where an individual tends to focus on what is happening around them, rather than paying attention to their internal state) (Parker et al. 2003). Provider-level barriers include knowledge about autism in adults, willingness to alter communication (e.g. allow the patient to use written notes), and openness to providing accommodations to healthcare provision. System-level barriers include availability of support to the patient, complexities of navigating the healthcare system, and stigma about autism (Vogan et al. 2017).

Two recent reviews identified a small number of studies from the EU, North America, and Australasia that investigated the barriers to healthcare access for autistic people. In their systematic review, Mason et al. (2019) reported that patient-provider communication, sensory sensitivities, and executive functioning/planning have an impact on the success of a healthcare visit. Bradshaw et al. (2019) concluded that, in addition to barriers to access, more autism-specific training and autism-friendly environments could improve healthcare access for autistic people. Other important factors in addition to the stated barriers include beliefs or behaviours that autistic people have in relation to healthcare. For instance, healthcare self-efficacy has been reported to be significantly lower for autistic people, compared to the general population (Nicolaidis et al. 2013). Satisfaction with patient-provider communication has also been reported to be lower for autistic people, compared to the general population (Nicolaidis et al. 2013). Furthermore, when considering the family context, parents of autistic people report giving up on services, not being able to access autism-specific services, or paying to provide services for their autistic child (Anderson et al. 2018).

Clinicians may, or may not, be aware of these patient-level barriers to healthcare – but are likely aware of the provider- or system-level barriers outlined above. For instance, some clinicians in the United States report that financial/time constraints impact upon their desire to accept a referral to see and treat an autistic patient (Warfield et al. 2015). Clinicians in the same study also noted that the transition to adulthood often meant there were fewer services to support autistic adults, and that more training and experience working with autistic patients is needed in medical education (Warfield et al. 2015). Whilst some studies have found that clinicians have a good knowledge of the characteristics of autism (Crane et al. 2019; Unigwe et al. 2017; Warfield et al. 2015; Zerbo et al. 2015), it is possible that this knowledge is not ‘used’ during the consultation. The clinician may have an image of what an autistic person ‘should’ be that may not relate to the autistic patient they are currently speaking with. For instance, atypical social communication is a characteristic of autism, but many autistic people report working hard to manage their social presentation in order to appear ‘neurotypical’ (Hull et al. 2017).

This study was part of a wider project that aimed to design interventions to improve autistic people’s access to healthcare. Previous research studies have separately explored healthcare barriers from the perspective of autistic people, and clinicians. Taking a novel approach, we aimed to simultaneously explore healthcare experiences from the perspective of both autistic people and clinicians, and investigate similarities and differences in opinions – such a study has not been undertaken to date. We also aimed to identify different and shared perspectives of the two groups towards healthcare experiences, thus informing clinicians about key factors that may improve healthcare interactions.

METHODS

This study was part of a broader UK programme of research about the health of autistic people, and used a qualitative research design. A series of focus groups were conducted with autistic people, and one supporter (‘participants’ or ‘supporter’). One-to-one interviews were conducted with healthcare professionals (hereafter ‘clinicians’).

Recruitment

Autistic people were eligible to take part if they were aged 18 years or older, and had an existing autism spectrum diagnosis. Participants’ diagnoses were self-reported and not confirmed by the research team. We used an online social media advertisement to recruit autistic participants and supporters. This advertisement was sent out once, and a reminder closer to the planned dates for the groups. Autistic people were encouraged to contact the research team with their availability and any reasonable adjustments that would facilitate their attendance.

All local clinicians (primary, secondary, or tertiary care) who delivered healthcare to autistic patients were considered eligible. Given the broad eligibility criteria for the professional sample, for efficiency, clinician participants were initially recruited through the research team and local networks which allowed for some targeting of participants with sufficient experience to provide rich accounts of experiences relevant to the study. This then allowed expansion of the sampling through a snowball approach. Further, given the broad range of views we sought clinicians employed in a variety of roles including nursing, psychiatry, dentistry, ophthalmology etc.

Participants

All participants lived in the North East of England. Table 1 describes the characteristics of autistic participants who took part in the study (6 males and 5 females, age range 29-65 years; 5 participants declined to provide 'age' information, one gave an approximate age). One participant attended with a supporter (the participant's mother). Participants had a range of occupations: two were employed (full time, or self-employed); one was a full time student; two were not working, and one was retired (five participants did not provide information about their occupation). Three participants were married, one lived alone, one lived with their partner, and one lived with their relative (five participants did not provide information about their living status).

Clinicians

Clinicians were recruited from a range of professions, so views from generalists and specialists were represented: Primary care physicians (General Practitioners (n=4), Nurses (n=5), Psychiatrists (n=1), and Ophthalmologists (n=5)). The study was not designed to investigate differences in opinion between clinicians from different professions. All clinicians had experience of providing healthcare to autistic people.

[Table 1 about here]

Procedure

Focus groups (duration 90-120 minutes; mean 100 minutes) and interviews (duration 30-60 minutes; mean 40 minutes) followed a semi-structured topic guide; follow-up questions were used to elaborate upon initial responses. In one focus group, the supporter of an autistic person attended. Clinicians were interviewed face to face. Written consent was obtained from all participants prior to commencing. Please see supplementary material 1 for the topic guides.

There were two participants in the first focus group; six participants in the second focus group; and the third focus group had four participants. At the beginning of the focus group general introductions were made, and the topic of the focus group was introduced. After the opening questions the focus groups were participant led; as participants raised new topics the researchers used additional questions to gain more information. In order to collect information from all participants as equitably as possible, the researchers posed questions/issues raised by some participants to others in the group.

Interviews were audio recorded. Only two of the three focus groups were audio recorded as one participant did not give consent for recording. In this instance, two researchers made detailed notes of participant responses; notes were then checked and agreed by both researchers. All other interviews and focus groups were transcribed by investigators.

By the final focus group there appeared to be no new points about healthcare experiences being made by the autistic participants. Likewise, towards the end of the clinician interview series there appeared to be no new data/ points about healthcare experiences being made by participants. Thus, given we used slightly different probes at each focus group to guide the discussions towards areas we had not heard much about, we determined we had achieved adequate data saturation.

Data analysis

Data were analysed using the framework analysis method described by Lewis and Ritchie (2003). This method identifies commonalities and differences within the data, before focusing on the relationship between the data. This allows for explanatory conclusions to be drawn from the qualitative accounts (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The third focus group (that was not recorded) was analysed in the same way as the two focus group transcripts; this was deemed to be acceptable to both researchers (DM and TB) who were present for the full duration of the focus group. This decision was made based on the comparison of each researcher's independent written notes taken during the group; not only was the content equivalent, but the statements made by each participant were accurately recorded (there were no disagreements over what was said by each participant). DM and HB generated initial open codes of the data. DM coded the autistic participants' transcripts; HB coded the clinicians' transcripts. A working analytical framework was then derived from the open codes by DM (one framework for each participant group). Three members of the research team (DM, CW, and CM) then independently applied the initial coding framework to a small portion of the data. DM has conducted similar research previously to identify the validity of quality of life measure for autistic people (McConachie et al., 2018). CW and CM are autistic people who helped refine the coding framework; they brought their own perspectives as autistic people to the analysis. The wider research team (JP, BI, MWS, IJ) considered the validity of the coding framework. Subsequently a second iteration of the coding framework was applied to a different portion of the data, and a final coding framework was developed. The reliability of the coding was established at this stage. Once the coding framework was refined CM, CW, and DM each independently coded another small portion of the data. DM compared the proportion of agreement between each portion; agreement was over 85% between each rater. DM then coded all of the transcripts using the appropriate framework. The final step was to create a coding matrix; this is a visual representation of how codes are endorsed across participants.

Ethics

A favourable opinion for this study was given by the Research Ethics Committee Wales REC 5 (18/WA/0191).

Community Involvement Statement

Three of the authors of this manuscript are autistic: DM, CW, and CM. There was no other community involvement for this manuscript.

RESULTS

Nine themes emerged from the autistic participants' data; eight themes emerged from the clinicians' data. Three key themes were identified by both autistic participants, the supporter, and clinicians: healthcare provision (describing symptoms, waiting for appointments, and patient-provider relationships), adjustments to healthcare, and the importance of an autism diagnosis to access appropriate healthcare. Table 2 shows themes of relevance to the research aims of this study. We

present below three of the prominent themes from the autistic participant group, two themes from the clinician group, and the three themes that were considered important by both groups.

[Table 2 about here]

Themes discussed by autistic participants

Cognitive factors: Many autistic participants discussed difficulties or challenges with processing information during appointments, or providing information requested by healthcare staff:

“You want to tell them things, but your mind empties, you can’t find the right words... I know he [the clinician] doesn’t want the literal answer... ‘What brings you here today?’, I know he doesn’t want to hear ‘the bus’”. [Participant 4]

Patients also described that providing information to clinicians can be challenging. This can involve difficulties describing symptoms:

“People think if you’re really sensitive you must be really in tune with the slightest twinge, you know where it is... but I don’t know what’s wrong. Or how to articulate it.” [Participant 9]

Another challenge was around memory, particularly remembering appointments. This kind of challenge was less often expressed by participants, but is highly relevant in terms of accessing healthcare:

“You’ve forgotten about the appointment entirely... I’ve turned up and I’ve been told my appointment wasn’t for another month... I’ve written it down on the wrong day or the wrong month” [Participant 10]

Patient characteristics: Participants discussed an array of beliefs about healthcare, and accessing healthcare, or behaviours used to engage with healthcare. For instance, some participants found it hard to express their needs in appointments, whereas others described being determined to get help with their symptoms:

“It’s really hard to speak up then, and I end up going along with whatever the doctor says. I’ve ended up with about four courses of antibiotics that I don’t want, all because I say what I think the doctor wants to hear” [Participant 3]

“The doctors don’t know what it is. ‘You’ll have to live with it’, well that’s not really what I want to hear... until you find out what it is I’m not going to stop pestering you” [Participant 10]

Two participants described specific instances of self-managing their health conditions. One acute case involved a participant who sewed together a cut in his foot. His reasons for doing so were:

“First thing, it was a Sunday. I wasn’t driving at the time... Second thing was I could have fixed it quicker, and be back on my feet... I have a fairly high pain tolerance” [Participant 7]

Moreover, some participants also found it hard to know when a healthcare visit was warranted:

“When I go... is it worth it? Is my visit worth what I’m going to go there for? Usually when I do go it’s because I suffer from other things as well. I have to go there anyhow.” [Participant 2]

Healthcare professionals: Participants often discussed their positive or negative interactions with healthcare professionals. Many participants expressed the opinion that healthcare professionals do not have good knowledge about autism:

“I think there’s a lack of awareness not only of autism spectrum disorders... I think they don’t really realise how external factors, the noise, the heat, smells.” [Participant 1]

Autistic people also reported encountering stereotypical, or incorrect, views about autism:

“Or they say you don’t have it because they met someone once with autism and you don’t fit into their image of what an autistic person is” [Participant 5]

Participants also discussed encounters with healthcare professionals that were positive, and described what attributes the clinician displayed. These often revolved around time, asking what the clinician could do for the participant, and listening:

“I went, and I sat there, and I just cried. For an hour. That’s all I did. Sob... He didn’t say anything, even for the hour... He then asked what would help me. What did I want? I said ‘this will help me, this will really help’... As I was leaving he put an arm around me and said ‘we’ll do this together’. That was worth more than anything he could have given me... because then I felt like he understood. He got it. So... that’s what makes the difference” [Participant 10]

It is clear that autistic people have widely different experiences of accessing healthcare – both positive and negative interactions with healthcare professionals were discussed. Some autistic people see their diagnosis as a way to enhance their self-advocacy; whereas others found it difficult to speak up for themselves. However, one consistent issue was with cognition; many reported problems with memory or managing their social presentation and conversations (such as anticipating what they wanted to say to the clinician, or having problems with literal language).

Themes discussed by clinicians

External service availability: Clinicians discussed the services available to autistic people (or a lack of services) and the disconnect between services that meant autistic people were passed from service to service.

“So I think [my colleague] was very acutely aware that people with autism drop into our mental health services and they shouldn’t be here because autism isn’t a mental disorder but it’s kind of where do you place these people and that just kind of compounds their confusion” [Clinician 4]

Yet, clinicians did also mention some ways that helping autistic people navigate the health system could be achieved:

“If there was somebody in the system who could stay up to date... and the care navigators can pick up on that, so there can be people who if they knew there was a particular fund or a particular third sector group in the community that they are aware of then yes, absolutely” [Clinician 14]

Within service healthcare resources/constraints: There was a lot of discussion about the constraints placed on services and healthcare professionals. Some clinicians discussed the waiting lists of diagnostic services for autism:

“So whether he’s waiting for another 15 months I don’t know but I’d probably chase that up now. But, they’re a diagnostic service, what are they going to do for him?” [Clinician 1]

More pressingly, the time constraints on appointments were frequently mentioned:

“Whatever your opening line is... if the person sits back and says “well actually I’ve got loads of things”, then my response for that might be “well look I’m really sorry I may not manage loads of things” [Clinician 14]

Some services reported financial constraints that could affect their practice. One clinician explained that those entitled to free eye tests put the clinicians in a difficult position:

“I think there is no lie about it, we get paid a pittance for an NHS [National Health Service] sight test... and you can’t really afford financially in a business sense to spend more than 20 minutes” [Clinician 12]

Finally, some clinicians described the top down pressures placed on healthcare professionals:

“It’s a whole new political thing isn’t there... what I am contracted by the NHS, and in their contract I need to do all the tests which I think is necessary, but if I didn’t look in the optic nerve or if I didn’t look at the lens of the eye they would want to know the reason why. So there is that thing of forcing tests on somebody” [Clinician 13]

The results show clinicians are concerned with factors that constrain their practice. These constraints were either a lack of available services to refer autistic patients to, or that there are considerable pressures on time for appointments. These factors clearly have an impact on how a clinician can provide healthcare for an autistic patient.

Themes discussed by both groups

Healthcare provision: Healthcare provision was the most discussed theme. This included describing symptoms, waiting for appointments, and patient-provider relationships. Both groups discussed the importance of continuity of care for building a good patient-provider relationship:

“Yeah, you’ve got to see the same person. Whether they’re right or wrong, you’ve got to see the same person, otherwise you’re just getting pushed round the system.” [Participant 2]

“Trying to make it so there is continuity of care building a relationship with the practitioner so they don’t see someone different every time which is good practice anyway” [Clinician 8]

Continuity of care is considered good practice. However, continuity in the patient-provider relationship seemed to be especially important for autistic patients. For instance, autistic participants often discussed problems with describing symptoms to healthcare professionals (a difficulty that may be reduced by repeatedly seeing the same clinician):

"I'm not quite sure what it is they actually want... 'have you got a pain', 'yes'. That's straight forward. 'Where is it?' well it's in my side. 'Right, is it a sharp pain, or is it an achy pain?'... 'what the hell are you on about now?'" [Participant 10]

One clinician thought that autistic people frequently attended appointments because of the worry associated with a possible physical condition:

"... as a GP... It's anxiety about something physical, but it's not actually the physical thing they're coming in for, it's the worry about it." [Clinician 4]

The challenge of interpreting symptoms was raised, or that cognitive style might make it difficult to explain the meaning of symptoms:

"Maybe some people having more obsessional thinking about certain conditions, maybe for example the interpretation of symptoms... and perhaps someone with an autism spectrum condition may have a very rigid view of what that might be" [Clinician 9]

Autistic participants mentioned their difficulties with waiting rooms, due to either sensory stimuli, or unwanted social interaction:

"When you do get the appointment you're in a waiting room and you can't always get space to yourself, kids are screaming and it's too noisy" [Participant 1]

"When your name is called, everyone points to where you have to go... Why do they do that? Why are they bothering with my appointment? It's my appointment, it's unwanted social interaction" [Participant 5]

Clinicians reported that healthcare provision could be more successfully delivered if the autistic person asked for adjustments:

"I think just them being aware that [asking for adjustments] we're not going to be offended, that sort of thing... We've heard it before and we're not going to react badly to them saying "please don't look at me" [Clinician 2]

However, one clinician also reported that a patient who comes to an appointment with an exhaustive list of symptoms could make an appointment challenging:

"But I might experience somebody who comes in with 40 handwritten sheets and me not reading it... they might get very offended by that or they may think that means I don't think the other things are very important... I'm trying to make a plan with you." [Clinician 4]

Adjustments to healthcare: Both autistic participants and clinicians were asked about the role of adjustments in making healthcare more accessible, or what else could make healthcare accessible. Both groups discussed adapting the area where the autistic patient waits for their appointments (even if this process did not always work):

"Even waiting outside, waiting in the [fresh] air which I've done that before my appointments come up but they don't [always] come out and get you... Some of them, do come out the door and shout for you" [Participant 11]

"The reception staff would know that certain patients need to wait outside to be called in, and will go out to collect them. Or we might sit them at the bottom of the stairs, away from the main waiting room" [Clinician 1]

Some clinicians did point out that some adjustments are effective and require minimal effort or resources:

“The whole consultation was done standing up. He was holding my ophthalmoscope, I was talking to the ophthalmoscope rather than him because he was more comfortable... you just have to adapt to that really.” [Clinician 2]

Autistic participants described highly diverse requirements for their adjustments. For instance, in hospital settings some wanted to be away from main wards or busy places, whereas others required that. The underlying theme usually involved managing anxiety:

“I was freaked about the idea of a general anaesthetic. They showed me the room in advance so I’d know where I’d be, they said other people could be there... [my mother] was there... I was shocked at how aware, she [the surgeon] was very aware” [Participant 6; female]

This participant did not want general anaesthetic as she wanted to have “all of the relevant data” about her physical state. Thus, the prospect of surgery was a huge challenge and the surgeon was very responsive to that need – showing the participant the operating theatre, and arranging for a supporter to be on hand.

“I wanted to be somewhere where I could see what was going on, and if anything looked like it might be a problem I could deal with it. It was to help manage my anxiety” [Participant 3]

However, one autistic participant did express concern that making such visible adjustments for autistic people could be problematic:

“I think that would cause more hostility. Because other patients will say ‘why are they getting preferential...’ favouritism and whatnot. So that would cause a whole other load of problems” [Participant 11]

Some clinicians described flagging systems that contained information relevant to providing adjustments:

“Every member of staff who brings up that record will get that prompt... it flags to us that it’s different and you need to think about... what support they might get.” [Clinician 10]

One clinician suggested that a system that provided tailored information about the patient would be useful:

“The person comes in with instructions, which say ‘I have this condition, this condition has an impact on me in this way as an individual with communication and I need the assistance of this person with me’ or ‘I may need help remembering what is said, by involving this person at the end’” [Clinician 10]

One system used to identify adjustments was discussed – the Autism Healthcare Accommodations Tool [AHAT]; <https://autismandhealth.org/?p=ahat>). One clinician reported this would work well:

“It looked very interesting because it would kind of, it would give your clinicians a heads up to say how I like to be treated, which is actually really nice for anybody. If we could do that for everybody and say “this is me. I like to be treated like this” [Clinician 4]

Autism diagnosis: Autistic participants and clinicians both discussed how a diagnosis of ASD might affect healthcare appointments. Many participants and clinicians discussed the benefits of having a diagnosis of ASD, and that a diagnosis could be empowering:

“My head used to be spinning all over the place. I didn’t know how to calm down, I didn’t know how to this that... That’s it, you know. My diagnosis helped me sort my head out, sort my mind out” [Participant 2]

“Since the diagnosis I’ve thought, come on now you have to say that this isn’t working for you. So after the diagnosis when I went to the surgery and it was full, the waiting room... I have autism and I don’t cope very well with the noise and lots of people, can I sit in the conservatory?” [Participant 10]

Or, from the perspective of one clinician, an autism diagnosis was considered a protective factor against being judged for one’s behaviour:

“Not just ‘there’s Mr Smith he’s downright awkward and very intransigent’... versus ‘that’s Mr Smith the reason he needs that care in that way is because...’ people [professionals] think of autism in terms of children” [Clinician 18]

However, one participant reported that their diagnosis of autism may impact negatively on the quality of their healthcare:

“Because if you go in as an autistic and give them every symptom under the sun I’m pretty certain I’m labelled as hypochondriac. Which means they then don’t listen” [Participant 6]

However, not everyone saw clear advantages to being diagnosed with autism at an older age. A palliative care nurse thought that bringing up the possibility of an autism diagnosis (to someone without a formal diagnosis) might not be important:

“That would be, and because of age, if someone’s older and they’ve missed an opportunity for a diagnosis, that you might think that they would have had it or it’s too late for an older person. I’m just thinking what others might think.” [Clinician 8; palliative care nurse]

Both autistic people and clinicians discussed the need to alter healthcare provision to make access easier for autistic people. Our data highlight that both groups don’t necessarily require extensive adjustments, and that small adjustments can be easily provided and beneficial. However, clinicians emphasised the need for adjustments to be reasonable; and one autistic person was conscious that obvious adjustments could be stigmatising. Finally, autistic people often discussed the sensory sensitivities around waiting rooms; or the potential for unwanted social interaction. These aversive experiences may have a negative impact on an autistic person’s willingness to engage with healthcare.

DISCUSSION

This study describes for the first time the qualitative healthcare experiences of both autistic people, and healthcare professionals who provide care to autistic people. This study found themes that were raised by autistic people, and others raised by health professionals. Three key themes were considered important by both autistic people and clinicians: Healthcare provision (describing symptoms, waiting for appointments, and patient-provider relationships), adjustments to healthcare, and the importance of an autism diagnosis to access appropriate healthcare. We suggest that health professionals, managers and commissioners/funders of healthcare wishing to make alterations to their services should focus first on aspects of healthcare provision described above, and the adjustments/accommodations that autistic people and clinicians think would be important

for them. This would improve healthcare access and may improve health outcomes – reducing morbidity and early mortality. The third cross cutting theme (autism diagnosis) is important – but as autism diagnostic assessments are often undertaken by specialist clinical teams, improved access to diagnosis may not be deliverable by teams focused on aspects of physical or mental health. Importantly, the adjustments mentioned by both groups are inexpensive, and relatively easy to implement.

Two clear issues with accessing healthcare were waiting rooms and continuity of care. Many autistic people discussed the problematic nature of waiting for appointments at healthcare settings. Autistic people have described why waiting experiences are aversive, for instance, sensory sensitivities (e.g. to light, noise, or smell) or being too busy (Bradshaw et al. 2019; Dern and Sappok 2016; Mason et al. 2019; Saqr et al. 2018). Several participants had either been given, or would like to be offered, alternative waiting arrangements. Clinicians who offer adjustments such as alternative waiting spaces will likely improve the healthcare access of autistic people – and in turn, improved access will likely result in better health outcomes.

The importance of continuity of care for the relationship between the autistic patient and clinician was clear. Participants and clinicians recognised the importance of maintaining patient-provider relationships. One participant noted this was to avoid being “pushed around the system”. Clinicians who can provide this continuity of care are likely to improve the health outcomes of autistic people – something that has been documented in the general population (Cabana and Jee 2004; Maarsingh et al. 2016).

Clinicians should be aware that cognitive factors can have an impact on healthcare visits. First, many autistic participants reported cognitive strategies to cope with healthcare visits (such as rehearsing conversations), but also that these strategies may not work (for instance, being ‘derailed’ when the conversation does not go as planned). This may be explained by the recently proposed framework of compensation. Compensation refers to the discrepancy between observed behaviour and the underlying neural/cognitive processes generating that behaviour (Livingston and Happé 2017). This means that an individual can express typical behaviour, despite underlying cognitive processes being atypical. Compensatory strategies were described by some participants, who discussed trying to script conversations with healthcare professionals; the intuitive back- and-forth of conversation is not available to some autistic participants in this study, and so they try to anticipate the flow of conversation in advance. The clinician may therefore consider that a patient appears to be conversant and fully engaged with their healthcare discussion; yet, key information may be missed.

Second, many participants described difficulties with remembering appointments, and found strategies to help organise them (such as writing down the appointment) equally problematic. A recent measure by Raymaker et al. (2017) – the Barriers to Healthcare Checklist – includes an executive functioning element that encapsulates many of the cognitive difficulties mentioned by participants in this study (for a review, see O’Hearn, Asato, Ordaz, & Luna, 2008). In sum, the consequences of these cognitive factors may impact on how information is processed in an appointment. Autistic people may leave an appointment without asking questions that are important to them. Alternatively, they may go along with what the clinician says, even if their own needs are not expressed or met. This further emphasises that clinicians may need to adjust their practice by taking the time to check in with the autistic patient, or being prepared to share information in a different way (e.g. a written summary of the appointment) that will allow the autistic person to process the information more thoroughly. These small changes may have a considerable impact on the success of healthcare visits for autistic patients.

Many autistic participants reported that clinicians had incorrect or stereotypical knowledge of autism and some clinicians reported a lack of training about autism. This broadly reflects the literature with a recent review highlighting that some clinicians – including psychiatrists, physicians, dentists, and nurses – have limited knowledge and personal resources to provide appropriate healthcare to autistic people (Morris et al. 2019). However, Unigwe et al. (2017) report that General Practitioners (GP) in the United Kingdom have a good knowledge of characteristics of autism, but lack confidence to deliver care to autistic patients and Crane et al. (2019) reported that psychiatrists had a good knowledge of autism, received good training, and reported confidence in providing healthcare to autistic people. Thus, there is a discrepancy between autistic people’s reports of clinician knowledge and some empirical data about clinician’s knowledge. What seems most likely is that clinicians’ knowledge is likely variable both within and between professions – and that to improve the situation, training about autism is needed for all health professionals (something the UK National Health Service is progressing for all professionals who work in relevant organisations). For all clinicians, listening to the unique views of each patient may be time consuming (particularly for those in primary care who said time was a considerable constraint) but is likely to improve the patient-provider interaction. As noted by participants, listening to the autistic person was reported to be the best form of interaction. Future research could explore how clinicians’ understanding of autism drives interactions with autistic patients, particularly when the autistic patient does not conform to a widely understood view of ‘what an autistic person is like’.

Some autistic people reported that their physical symptoms were potentially overlooked by professionals. In one case an autistic person was diagnosed with a mental health condition but later that symptoms were ascribed to a cyst, leading to inappropriate medication and delayed investigation. One clinician did discuss that autistic people can attend appointments not for physical health symptoms per se, but rather for worry about those symptoms. A second clinician thought that, due to the way autistic people think, an autistic patient might misinterpret the nature of their symptoms. These reports suggest that clinicians appropriately look for other explanations for the symptoms being described to them – but that this can sometimes lead to misdiagnosis.

Participants also reported clearly knowing when their discomfort was a physical pain, but did have difficulty localising or describing their symptoms. As stated in the introduction this may be explained by alexithymia, which is common in autism (with 40 – 65% of autistic adults meeting the cut-off for alexithymia; Bird & Cook, 2013). Alexithymia has also been associated with medically unexplained symptoms, which are reports of physical symptoms not associated with underlying physical causes (Deary et al. 1997; Kooiman 1998). In the future, research should seek to investigate how alexithymic traits might affect descriptions of symptoms in healthcare visits. In conclusion, clinicians should be aware that (particularly) for autistic people, repeatedly reported symptoms may be due to anxiety around physical symptoms, but may also be due to genuine physical causes that require treatment. Existing tools (e.g. information gathering forms to be completed by autistic patients) could be used to scaffold healthcare visits and help the patient describe symptoms (Raymaker et al. 2012).

Strengths/limitations

This study collected data from both autistic people and clinicians, using a same semi-structured topic guide. By approaching specialists as well as generalists (e.g. palliative care professionals and ophthalmologists), views that may be more representative of a range of health professionals were obtained. We did recruit more ophthalmologists than expected, relative to the overall sample size.

Some of the ophthalmologists described a work environment more conducive to trying new health care delivery approaches or being involved more in research (e.g. relatively fewer time/resource constraints). These factors may explain the over-representation of ophthalmologists in the group. However, it is important to consider that we did not recruit many specialist medics, or healthcare practitioners more likely to be in frequent contact with autistic people (e.g. psychiatrists); thus, it is unlikely that our findings are generalizable to these healthcare professions. A significant strength of this study was the participation of older autistic people, whose healthcare access and needs may differ from younger people. Regarding limitations, all clinicians were drawn from the North East region of England and it is unclear how generalizable the present findings are to people from other geographical areas (both within the UK and internationally). As different countries have different healthcare systems and funding mechanisms, investigation of whether the themes identified are valid in other countries would be informative. Not all clinical specialities were represented and thus the findings may not reflect the reality for all professionals (for example, their clinical training about autism, and their clinical environment). For the autistic participants whilst the findings did encompass positive and negative views about healthcare provision, the views of those who do not access healthcare were not elicited. Of those who provided relevant data around half were married, two thirds lived independently, and around half were employed or studying. These proportions are higher than often reported (Farley et al. 2018; Helles et al. 2017; Howlin et al. 2013). Further, we did not collect ethnicity data, measures of autistic traits, co-occurring conditions (e.g. mental health), or the number of times each participant engaged with the health service to better characterise the sample. Thus, our participants may represent a group more willing or able to attend research discussions. Therefore, the data here should be interpreted with these caveats in mind; future research should seek to replicate, or build upon, these findings in future studies.

Implications and conclusion

This qualitative study identified several key messages to help improve the healthcare experiences of autistic patients. Healthcare providers should take account of these findings when designing services, so autistic people are able to access usual care. By accessing care and receiving services, autistic people are more likely to receive care such as immunisations and other public health interventions, participate in screening programmes, and receive the cutting edge treatments that are being designed to treat long term conditions. Both clinicians and autistic participants identified continuity of care as vital for building a positive patient-provider relationship. Also, small adjustments to the healthcare visit, or waiting arrangements, can have a positive impact. Our findings suggest that healthcare provision may be improved in several ways: making adjustments to provision that are reasonable for both parties (for instance, offering alternative waiting locations); listening to the unique characteristics of the autistic patient (for instance, if they need to communicate in a different way); be aware that some autistic people have difficulty describing their symptoms and that not all reported symptoms are inflated by worry; and recognise that autistic people's cognition is often atypical. Taking some or all these aspects into account would substantially improve access to healthcare, and the healthcare experience – in turn, this may improve health outcomes, reducing morbidity and early mortality.

Author roles:

BI was Chief Investigator. BI and JP led the application for funding, BI oversaw governance and both BI and JP co-designed the study and supervised the research team. Recordings were transcribed by DM, CW, HB. The initial, open coding, was conducted by HB (clinicians' data) and DM (autistic participants' data). DM and TB conducted all focus groups; TB conducted all interviews. BI, JP, MWS, IJ, and TB all reviewed and amended the initial coding framework; CW, DM, and CM iteratively refined the initial coding framework into the final set of codes. DM coded all transcripts; CW and CM coded 10% for reliability checking. DM drafted the manuscript; all authors reviewed and finalised the manuscript.

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- Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics*, 141(Supplement 4), S300-S305.
- Bird, G., & Cook, R. (2013). Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism. *Translational psychiatry*, 3(7), e285-e285.
- Bishop-Fitzpatrick, L., & Kind, A. J. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3380-3391.
- Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. *Research in autism spectrum disorders*, 63, 34-41.
- Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How can we support the healthcare needs of autistic adults without intellectual disability? *Current Developmental Disorders Reports*, 6(2), 45-56.
- Cabana, M. D., & Jee, S. H. (2004). Does continuity of care improve patient outcomes. *J Fam Pract*, 53(12), 974-980.
- Cashin, A., Buckley, T., Trollor, J. N., & Lennox, N. (2018). A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*, 22(1), 96-108.
- Crane, L., Davidson, I., Prosser, R., & Pellicano, E. (2019). Understanding psychiatrists' knowledge, attitudes and experiences in identifying and supporting their patients on the autism spectrum: online survey. *BJPsych Open*, 5(3).
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., et al. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823.
- Deary, I. J., Scott, S., & Wilson, J. A. (1997). Neuroticism, alexithymia and medically unexplained symptoms. *Personality and Individual Differences*, 22(4), 551-564.
- Dern, S., & Sappok, T. (2016). Barriers to healthcare for people on the autism spectrum. *Advances in Autism*.
- Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research*, 11(1), 142-152.
- Foley, K.-R., Pollack, A. J., Britt, H. C., Lennox, N. G., & Trollor, J. N. (2018). General practice encounters for young patients with autism spectrum disorder in Australia. *Autism*, 22(7), 784-793.
- Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism*, 21(4), 458-469.
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232-238.
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological medicine*, 49(4), 559-572.
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(6), 572-581. e571.
- Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., et al. (2017). "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534.
- Kooiman, C. G. (1998). The status of alexithymia as a risk factor in medically unexplained physical symptoms. *Comprehensive Psychiatry*, 39(3), 152-159.

- Livingston, L. A., Colvert, E., Team, S. R. S., Bolton, P., & Happé, F. (2019). Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder. *Journal of Child Psychology and Psychiatry, 60*(1), 102-110.
- Livingston, L. A., & Happé, F. (2017). Conceptualising compensation in neurodevelopmental disorders: Reflections from autism spectrum disorder. *Neuroscience & Biobehavioral Reviews, 80*, 729-742.
- Maarsingh, O. R., Henry, Y., van de Ven, P. M., & Deeg, D. J. (2016). Continuity of care in primary care and association with survival in older people: a 17-year prospective cohort study. *British Journal of General Practice, 66*(649), e531-e539.
- Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., et al. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of Autism and Developmental Disorders, 49*(8), 3387-3400.
- Morris, R., Greenblatt, A., & Saini, M. (2019). Healthcare providers' experiences with autism: a scoping review. *Journal of Autism and Developmental Disorders, 49*(6), 2374-2388.
- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., et al. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of general internal medicine, 28*(6), 761-769.
- Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., et al. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism, 19*(7), 824-831.
- O'Hearn, K., Asato, M., Ordaz, S., & Luna, B. (2008). Neurodevelopment and executive function in autism. *Development and psychopathology, 20*(4), 1103-1132.
- Parker, J. D., Taylor, G. J., & Bagby, R. M. (2003). The 20-Item Toronto Alexithymia Scale: III. Reliability and factorial validity in a community population. *Journal of psychosomatic research, 55*(3), 269-275.
- Raymaker, D., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A., Kripke, C., et al. (2017). Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism, 21*(8), 972-984.
- Raymaker, D., Nicolaidis, C., Baggs, A., Boisclair, C., Kripke, C., Ashkenazy, E., et al. (2012). Getting the Most out of Healthcare as an Autistic Adult.
- Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism, 22*(1), 51-61.
- Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *British Journal of General Practice, 67*(659), e445-e452.
- Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunsy, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal, 10*(2), 264-270.
- Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders, 46*(4), 1441-1454.
- Warfield, M. E., Crossman, M. K., Delahaye, J., Der Weerd, E., & Kuhlthau, K. A. (2015). Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders, 45*(7), 2209-2217.
- Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. *Journal of Autism and Developmental Disorders, 45*(12), 4002-4014.