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# Health Care Needs, Experiences, and Perspectives of Autistic Adults

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## Abstract

***Background:*** Autistic adults have high rates of co-occurring health conditions, suicide, and premature mortality, yet often experience health care barriers and poor health outcomes. A better understanding of the health care needs and experiences of autistic adults is essential for improving the health care system and patient experience.
***Methods:*** This study examined the perspectives of autistic adults regarding their health care experiences in primary care and other settings and their suggestions for improvement using both qualitative and quantitative methods. Twenty autistic adults (aged 18–35 years, 65% male) completed surveys and individual semi-structured interviews.
***Results:*** Qualitative data analysis results revealed 10 subthemes across 3 overarching themes: (1) system- and clinic-level factors affect access to care, (2) aspects of the clinic environment affect health care experiences, and (3) provider knowledge and practices affect health care experiences. Within the first theme, participants described barriers to obtaining services, including scheduling logistics, costs and inadequate insurance coverage, and transportation barriers. The second theme focused on aspects of the clinic environment that participants found especially relevant to their health care experiences and that required specific accommodations. This included sensory input, anxiety-provoking situations and procedures, and wait time. Within the third theme, participants emphasized aspects of providers' care that affected their health care experiences. Key factors included provider knowledge about autism, communication, rapport, and individualized care and patient–provider partnerships.
***Conclusion:*** Overall, the findings point to a need for provider training and improvements to the health care delivery system to better meet the unique needs of autistic adults.

**Keywords:** autism, adults, health care services, qualitative research, primary care, access to care

## Community Brief

*Why is this an important issue?*

Receiving good health care is important for health and well-being. Understanding autistic adults' perspectives on their health care experiences will help identify ways that health care services can be improved to better meet their needs and preferences in the future.

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*What was the purpose of this study?*

The purpose of this study was to learn from autistic adults about their health care needs, experiences, and suggestions for improvement.

*What did the researchers do?*

The researchers asked autistic adults in the United States to complete a survey and participate in an interview over Zoom. The survey and interview questions asked about their experiences receiving health care services and suggestions for how to improve health care services for autistic adults.

*What were the results of the study?*

Twenty autistic adults between the ages of 18 and 35 years participated in this study. Most participants were men (65%) and most were White (75%). The participants shared many important insights about their primary health care experiences and experiences in other health care settings. The results fell into main ''themes'' or ideas that people had in common. These themes are not listed in any particular order. Autistic adults described many factors that make it hard to access to care, such as getting an appointment, finding transportation, or paying for health care. They explained that the clinic environment needs to be better suited to their needs, such as having a quiet place to wait or sensory accommodations. Participants wanted their doctors to know more about autism and to be able to connect and communicate with them. They also wanted their doctors to partner with them to make sure their health care treatment plan is acceptable and understandable.

*What do these findings add to what was already known?*

These findings show that autistic adults in the United States face many barriers in receiving health care. Some recommendations for improvement may be helpful for all patients, such as being able to book appointments online or having a doctor who does not rush you. Other improvements need to be tailored to the unique needs of autistic patients, such sensory accommodations or autism training for doctors and clinic staff.

*What are potential weaknesses in the study?*

Because the study was small and only included adults who were able to share about their experiences during an interview, these results may not apply to all autistic adults. Another limitation is that the study was designed and carried out by non-autistic (allistic) researchers, who have different perspectives from autistic people. We asked participants to help us interpret our findings to help address this limitation.

*How will these findings help autistic adults in the future?*

The insights from this study provide a lot of recommendations about how health care services can be improved to better meet the needs and preferences of autistic adults in the future.

## Background

Autistic adults[1,]* experience a range of significant challenges that require comprehensive and coordinated health care services; however, studies have found that they often struggle to access and receive high-quality care.[2,3] The purpose of this study was to better understand the perspectives of autistic adults regarding their health care experiences, with a goal of identifying strategies for improvement.

Autistic adults often experience a number of co-occurring conditions that require ongoing health care services. These include mental health conditions, such as anxiety and depression, and medical conditions, such as seizures, gastrointestinal problems, sleep disorders, immune conditions, and obesity.[4–8] Autistic adults experience higher rates of both physical and mental health conditions than the general population[8,9] and appear to be at higher risk for premature mortality.[10] In addition, autistic adults are up to nine times more likely to experience suicidal ideation and are significantly more likely to attempt or die by suicide than non-autistic adults.[11–14] As such, receiving timely and appropriate prevention and treatment services is of utmost importance. However, many autistic adults have trouble finding and obtaining satisfactory health care services, resulting in significant unmet health care needs.[2,3]

Unfortunately, the current health care environment is not designed to appropriately accommodate the specific needs of autistic adults. Many autistic adults have differences in

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*At the beginning of each interview, we asked each participant which terminology they preferred to use the autism-specific language most comfortable to them. The majority (75%) said that they had no preference. Of those with a preference, most preferred person-first language (person ''with autism'' or who ''has autism''), whereas only one participant preferred identity-first language (i.e., autistic person). Given this diversity of perspectives among our participants, with most having no preference, we have followed recommendations of others in the field[1] and the journal's Manuscript Submission Guidelines and Policies to use identity-first language throughout the article.

language, communication, information processing, and sensory experiences.[15] Office staff and health care providers rely heavily on both written and spoken language to schedule appointments, obtain information about history and symptoms, and communicate complex health care information; yet, necessary communication accommodations are not always made available.[16] Health care clinics and facilities are often noisy and overly bright,[17] and the pain or discomfort inherent in medical procedures can be exacerbated for individuals with sensory sensitivities. Compounding these environmental problems, most health care providers have had little if any specific training or education in caring for autistic patients.[18–21]

As a result of these barriers, autism researchers, clinicians, and advocates have pushed for work that leads to a better understanding of and more quality care that meets the needs of autistic adults. A 2019 systematic review identified only six studies focused on barriers and facilitators to health care services for autistic adults.[22] Another recent systematic review focused on the same topic identified 13 studies, with only a few focusing specifically on the perspectives of the autistic adults themselves. The lack of consistency in methodology and lack of common metrics and variables of interest prohibited quantitative meta-analysis.[23] Despite the relatively limited number of studies to date, some common themes have emerged.

The most consistently reported health care barriers across prior studies of autistic adults have included patient-level factors (such as differences in communication, sensory experience, and pain responsivity), provider- or practice-level factors (such as provider knowledge, accessibility, and accommodations), and system-level factors (such as accessibility and service availability).[22–30] More recently, surveys and focus groups with autistic adults in the United Kingdom and Ireland have identified key recommended adjustments to health care services to improve patient access and experience. These include modifying the sensory environment, adjusting the clinical and service context, and increasing clinician knowledge and understanding.[31–33]

Despite increased attention to supporting the health care needs of autistic adults, relatively few studies have directly focused on the perspectives of autistic adults themselves, as highlighted in recent reviews.[23,32] These perspectives are critical for gaining a deeper and more nuanced understanding of health care needs and experiences of autistic patients and are essential for informing new models for health care training and delivery. Most recent research on this topic has been focused on health care experiences in the United Kingdom and Ireland,[31–33] whereas the health care experiences of adults in the United States have received relatively less attention,[22,23] with some exceptions.[26] The U.S. health care context involves a complex multi-payer financing system that includes a range of public and private insurance options as well as out-of-pocket costs.

Medicaid is the publicly funded insurance option for eligible low-income individuals and people with certain disabilities. An increasing number of autistic adults are enrolled in Medicaid[34]; yet, many health care providers do not accept Medicaid due to low reimbursement rates. In other cases, some providers may be not be contracted with all insurance plans (i.e., considered to be ‘‘out of network’’), resulting in higher out-of-pocket costs for patients. Additionally, many U.S. insurance plans have limits on coverage for different types of services and procedures. Given the substantial international differences in health care systems and services, a greater understanding of the experiences of autistic adults in the U.S. health care context would be helpful for informing practice and policy improvements.

The current study sought to contribute to this emerging body of knowledge by examining the perspectives of autistic adults in the United States regarding their health care experiences and suggestions for improvement. Non-autistic (allistic) researchers conducted the study using a qualitative approach to provide a deeper understanding of both positive and negative aspects of health care in the United States and to uncover unique and unanticipated insights and suggestions from autistic patients themselves.

## Methods

### *Study design*

We used a Postpositivism Framework to guide the development of this qualitative study and a phenomenological approach to describe the lived experience of autistic adults as they navigate the health care system, including both positive and negative experiences and suggestions for improvement.[35] We selected this approach because we sought to understand the essence of each adult's personal experiences and to arrive at common themes shared across participants.

### *Participants*

The sample included 20 autistic adults ranging in age from 18 to 35 years ($M = 25.6$, standard deviation [SD] = 5.1; 13 cis male, 6 cis female, 1 transgender female) living in the United States. The research team recruited potential participants by distributing flyers in-person and online through autism service providers, community groups, academic medical centers, and autism research sites. Eligibility requirements included being an adult between the ages of 18 years or older, having a diagnosis of autism spectrum disorder, and having the ability to understand and respond to interview questions. Study staff provided information about the study to potentially eligible participants using their preferred means of communication (phone or email) and shared a Study Information Form that provided written information about study participation. All participants provided informed consent before participating in the study. Participants received a $50 gift card for participation in the study. The institutional review board at the University of Virginia approved the study.

### *Procedures*

Participants completed a brief questionnaire online using the Qualtrics survey platform and participated in an individual qualitative interview. The sections below describe the measures and interview procedures.

Demographic survey. The research team created a brief questionnaire for the current study to assess individual characteristics, employment, living situation, and current health care services and providers.

Qualitative interviews procedure and interview guide. After completing the survey, participants shared more about their health care experiences and perceptions during individual qualitative interviews. The study used individual interviews with semi-structured question guides, as earlier work suggests that it is a more comfortable discussion format for autistic participants.[36–38] Interviewers followed a semi-structured interview guide in which 10 open-ended questions were followed up by specific probes when more elaboration and explanation were needed. The Interview Guide is included as the Supplementary Data.

The interview questions focused on experiences receiving health care services (including both positive and negative experiences with health care providers), satisfaction with primary care services, perceptions of primary care provider knowledge about autism, need for and quality of accommodations, suggestions for how health care services could better meet their needs, and suggestions for what providers need to know to provide better care for autistic adults. Research team members asked participants if they would like to receive a copy of the guide before the interview was conducted and provided it in advance when needed. Researchers offered participants additional accommodations (e.g., providing thoughts over email or method of their choice); however, all participants chose to complete interviews verbally via Zoom videoconferencing. The average interview length was 23 minutes (SD = 10.8), with a range of 10 to 53 minutes, and a median of 20 minutes.

### *Analysis plan*

Demographic survey. The research team used descriptive statistics (i.e., mean, SD, and percentage) to analyze demographic survey response data.

Qualitative interviews. The researchers recorded all interviews and had them professionally transcribed. The researchers then entered the transcriptions into a qualitative data analysis software platform (Dedoose, Version 8.3.35) for coding and analysis. The research team used a phenomenological analysis approach to identify important topics and patterns within the interview data.[35] All four members (the coders) of the analytic team (M.O.M., N.C.-Z., A.H., and E.S.) participated in data analysis using an iterative and collaborative process through multiple phases of discussion, coding, categorizing, theme development, and review.[39]

The goal of the first stage of data analysis (step 1) was for the analytic team to get familiar with the data and identify all quotes or statements that related to participants' health care experiences.[35] Each coder read all transcripts, recorded initial observations, and started to group individual quotes into clusters that described similar experiences (i.e., codes). The team met regularly to discuss initial codes and eliminate any discrepancies in coding. After multiple meetings, coders developed a codebook that identified and defined codes related to the health care experiences of autistic adults throughout the transcripts.

The next phase (step 2) included consistently analyzing the data (i.e., matching codes to actual text) across all transcripts. Two coders (A.H. and E.S.) coded all transcripts based on the codebook. To ensure that each coder was using the codebook similarly, coders utilized an application in Dedoose to assess inter-rater reliability or consistency in coding across coders. This is a structured form of consensus building that fits well into the Postpositivism Framework used within this study.[35] Coders tested their initial inter-rater reliability[40] by coding three interviews, with initial reliability of 0.71. After this, they met to discuss, review discrepancies, and come to a better understanding of the codes. They then coded an additional four interviews with overall reliability of 0.83. The coders again met to discuss, resolved all discrepancies, and came to agreement on 100% of the excerpts. After establishing reliability, the two coders independently coded the remaining transcripts. The research team met regularly to discuss coding and preliminary findings.

Finally, during step 3, the team grouped codes into main categories of key health care experiences and facilitators and barriers to positive experiences so that relevant themes addressing the research questions could emerge. Within phenomenological analysis, this helps get to the what and how of the experience under investigation.[35] The analytic team used data visualizations, including code co-occurrence and frequency, to assess code salience, to inform members' understanding of the connections between codes, and synthesize the data into themes. The team reviewed the coding analysis from step 2 and conducted axial coding to consolidate codes, clarify codes where needed, and identify final themes. The team then developed a final data report to outline, define, and provide example quotes for each theme. The final report included the three themes described in the Results section.

The study team also used member checking procedures to assess the accuracy of the qualitative results and seek additional insights.[41] The research team invited study participants to review the results of the study. Three participants took part in this process. Participants reviewed the final themes and provided feedback using their preferred method of review and communication (e.g., in writing, PowerPoint, or discussed over the phone). The research team then incorporated this feedback into the overall interpretation of results. For example, one participant noted that some of barriers described (e.g., insurance coverage and health care costs) are not unique to autistic adults and that we should specifically point out that addressing those would benefit ''everyone.'' Another participant suggested that we emphasize that each approach should be individualized (e.g., some find it helpful to have a family member present, whereas others do not) and that we emphasize the importance of training providers in how to work with autistic individuals.

## Results

Table 1 includes descriptive statistics for participant demographic characteristics. Participants ranged in age from 18 to 35 years ($M = 25.6$, SD = 5.1), and the majority were male (65%). Most respondents (85%) received regular primary care services. See Table 2 for descriptive statistics for health care-focused survey responses.

The results of qualitative analysis of individual interviews revealed 10 subthemes within 3 overarching themes: (1) system- and clinic-level factors affect access to care, (2) aspects of the clinic environment affect health care experiences, and (3) provider knowledge and practices affect health care experiences. Table 3 illustrates the themes, subthemes, and example quotes. Themes are indicated by subheadings,

Table 1. Sample Characteristics

| *Characteristic* | N *(%)* |
|---|---|
| Gender | |
| Male | 13 (65) |
| Female | 6 (30) |
| Trans-female | 1 (5) |
| Ethnicity | |
| Hispanic/Latino | 2 (10) |
| Race | |
| White or Caucasian | 15 (75) |
| Black or African American | 2 (10) |
| Biracial | 2 (10) |
| Residence | |
| Live alone | 4 (20) |
| Live with parent(s) | 8 (40) |
| Live with partner or spouse | 3 (15) |
| Live with roommate(s) | 2 (10) |
| Other | 3 (15) |
| Employment | |
| Full-time job | 6 (30) |
| Part-time job, student | 2 (10) |
| Part-time job, not student | 4 (20) |
| Not employed, not student | 8 (40) |

and subthemes are italicized within the text with illustrative quotes. Participant names and identifiers have been replaced by random initials throughout.

### *Theme 1: System- and clinic-level factors affect access to care*

The first overarching theme included three subthemes that related to barriers and facilitators to accessing health care services. These themes encompassed different factors that made it more or less difficult for autistic adults to obtain services. Many respondents identified barriers to access. By contrast, participants also shared examples of positive experiences and suggestions for improvement.

Table 2. Health Care Experiences

| | N *(%)* |
|---|---|
| Accompanied to health care appointments | |
| Yes, almost always | 10 (50) |
| Yes, sometimes | 2 (10) |
| No | 8 (40) |
| Receives regular primary care | |
| No | 3 (15) |
| Yes | 17 (85) |
| Receives specialty care | |
| No | 9 (45) |
| Yes | 11 (55) |
| If yes, specialist type(s) | |
| Endocrinologist | 1 (5) |
| Gynecologist | 1 (5) |
| Neurologist | 2 (10) |
| Otolaryngologist | 1 (5) |
| Psychiatrist | 7 (35) |
| Psychologist | 4 (20) |

Several participants identified health care *costs and insurance coverage barriers* as particularly important system-level roadblocks to accessing to care. As noted previously, the U.S. health care context involves a complex mix of both public and private insurance options as well as out-of-pocket costs. Several participants noted the complexity and lack of transparency in the system. BP observed that he believed ‘‘insurance companies [are] jacking up the price’’ and felt that ‘‘everyone would be better off regardless of disability … [if] hospitals could just charge a set amount instead of looking to their little big book of prices.’’

Participants expressed frustration at the effect of these issues on health care access. Many participants noted that they were unable to see preferred providers because of ‘‘red tape out of network’’ issues (SZ) or because the providers did not accept Medicaid or other insurance. For example, KR noted that he finds it ‘‘incredibly difficult’’ to find a knowledgeable provider who will ‘‘accept [my] insurance.’’ Other participants noted that high health care costs and copays prevented them from receiving the care that they needed. For example, LZ noted that her insurance coverage often determines the type of care she receives:

> My Medicaid … don’t pay for what I need … and usually limits, too … If I need to go to a dentist … for, say, an emergency filling? … There’s a cavity right now, but … this one dental plan, I can’t use until after six months … The most recent time I got the flu … I had to go to a different walk-in clinic when one couldn’t be afforded by my healthcare. (LZ)

The limits on insurance coverage for different types of services appear to be particularly challenging for autistic adults, many of whom need access to multiple types of providers. Some participants noted that mental health costs and insurance coverage are especially difficult. For example, SZ had to stop seeing her therapist because she ‘‘couldn’t afford the co-payments’’ after she ‘‘refinanced a new car and [her car] payments went up.’’ Another participant expressed similar concerns about mental health coverage:

> The fact that we don’t have, like I have decent insurance … so a $40 copay to see, um, like a therapist or something is, is too much, especially if they … want me to see ‘em like once a week or once every two weeks. (AH)

In addition to financial considerations, many participants noted that location and distance from the clinic were considerations when accessing health care. In fact, *location and transportation barriers* emerged as another key access-related subtheme. Some respondents explained that they selected providers who lived nearby, although this may be at the expense of quality. GS observed: ‘‘Where I live, the doctors aren’t that great’’; and explained that it takes him ‘‘about a hour and a half to two hours’’ to drive to his preferred providers. Other participants reported difficulty accessing even local health care services due to transportation barriers that are exacerbated for autistic adults who are unable to drive. For example, VW explained:

> I think they should improve on transportation, ‘cause not all the time my parents are, uh, feeling well enough to take me, and so sometimes I have to get in a cab with people I don’t know and then, I end up not going ‘cause it’s not comfortable, and so if they could provide transportation just specifically for people who need assistance.

TABLE 3. PERSPECTIVES ON HEALTH CARE EXPERIENCES: THEMES AND SUBTHEMES

| *Theme* | *Subtheme* | *Example quotes* |
|---|---|---|
| System- and clinic-level factors affect access to care | Costs and insurance coverage barriers | ''Difficult things right now would be my Medicaid or Medicare? … Like some of the things don't pay for what I need.'' (LZ) |
| | Location and transportation barriers | ''Where I live, the doctors aren't that great… Another doctor I had, she was very good at people like me … but she's all the way in [another city] … and I don't want to travel that far.'' (GS) |
| | Appointment scheduling barriers and facilitators | ''There are a few things that … are very helpful and would be helpful for other people on the autistic spectrum … And this is like, um, scheduling appointments online so you don't have to call in to the office.'' (KR) |
| Aspects of the clinic environment affect health care experiences | Sensory needs and accommodations during health care visits | ''With all the people, noises going on. That can be nerve-wracking … I would say maybe a separate waiting room [would be better] for people that can't tolerate all the noise.'' (JC) |
| | Managing anxiety and pain during health care visits | ''My doctor … jokes with me a lot to keep me smiling and focused because I'm afraid of needles and things like that.'' (HN)<br>''I think there could be … certain textured objects that either calms someone down, or it can distract them from some of the procedural things.'' (MJ) |
| | Wait time and visit length | ''Well, if you gotta wait a long time and the waiting room's crowded, it makes you just wanna leave or go home.'' (JC)<br>''I always feel rushed during the appointments and as I said, I get flustered and forget to, um, to ask about things or to, to mention things that I had meant to.'' (AH) |
| Provider knowledge and practices affect health care experiences | Provider knowledge of autism | ''I have no idea, honestly [how much they know about autism].'' (MJ)<br>''I don't think that health care providers that don't specialize in it really know what to look for, like, even basic signs of it.'' (KR) |
| | Provider rapport | ''I have a really good relationship with both the nurse and the doctor. And they always talk to me and take an interest in me.'' (JR)<br>''I just know I feel comfortable with Dr. [Smith] … It's being familiar with them.'' (LY) |
| | Provider communication during the health care visits | ''When I'm talking to doctors, there's some slight disconnect on what I'm trying to communicate and what they're sort of picking up on.'' (TF)<br>''Maybe they have to, maybe they'll have to explain stuff to us more than once … for us to understand.'' (EC) |
| | Patient–provider partnership | ''They let my mom come in the room with me … it makes me more comfortable.'' (JC)<br>''If there would be a way to … formulate that more easily I think people would definitely, you know, be more compliant with the recommendations.'' (KR) |

Even after managing financial and geographic barriers, many participants reported that the process of *appointment scheduling* was challenging. Some autistic adults may find the process of calling a doctor's office to make an appointment to be daunting or unsurmountable if they need or prefer other means of communication. As described by AH:

> I'm not very well spoken, like I, I can write much better than I speak. And so when I try, I get flustered and, um, especially talking on the phone … a lot of times, especially if the, if it's like a landline, um, voices on phones sound really distorted or garbled and, um, I do have auditory processing issues. So, basically just everything, everything about phone calls, I just, I hate … I put them off and … if I absolutely have to make them, I can, but it gives me like severe anxiety.

Other participants noted that the option to book appointments online was especially helpful for them.

> There are a few things that they do that I think are- are very helpful and would be helpful for other people on the autistic spectrum … like, um, scheduling appointments online so you don't have to call in to the office. (KR)

In terms of appointment availability, some reported that they were able to ''get in really fast'' (VW), whereas others described difficulty getting appointments when needed.

> Even if I tell the receptionist I'm sick and I, I'd like to actually see my doctor like today …, they're like, I'm sorry he doesn't have an appointment for six weeks. (AH)

### *Theme 2: Aspects of the clinic environment affect health care experiences*

All participants described aspects of the clinic environment that affect their overall health care experiences. A key subtheme was related to autism-specific *sensory needs and accommodations during health care visits*. Most participants described sensory needs and experiences that can pose challenges for them in the health care setting, including sensitivity to noise, ''chaos,'' light, smell, and touch. Several participants described negative health care experiences that directly related to sensory issues. For example, DC said ''I just don't like a lotta noise or lotta people and lotta light.'' JR noted: ''I hate it when [the doctor] does the knee tap thing,'' in reference to the patellar reflex test that is typically conducted as part of a medical examination.

Others specifically mentioned dental procedures that were difficult, including having to ''put up with the saliva dripping just a little bit, especially when you have that thing in your mouth for X-rays'' (SZ), or when dentists ''put that light in your face, when they're looking in your mouth? … that would like, always really bother me'' (KR). These experiences reveal that common medical procedures may be especially difficult for autistic adults without appropriate support or accommodations for their sensory needs.

Participants shared sensory-related accommodations that had been helpful for them, as well as suggestions for improvement, such as offering ''quiet'' (MH) waiting areas and addressing noise and light-related sensitivities. Regarding the waiting room, DC noted that she ''can't stand all them people out there, and that light. So, they take me back to my room to wait.'' Similarly, JC observed that ''all the people, noises going on [in the waiting room] can be nerve-wracking,'' and suggested that ''a separate waiting room [would be better] for people that can't tolerate all the noise.'' MJ recommended ''a noise-canceling machine'' in the clinic room to ''muffle sound outside.'' TF noted that he appreciates the softer lighting in his doctor's office, observing that ''their lighting isn't like the bright usual bright fluorescent doctors' lighting for most of the building.''

Similarly, many participants described difficulties *managing anxiety and pain during health care visits* that may also be particularly challenging for autistic patients. Examples ranged from social anxiety (making it difficult to navigate busy waiting rooms or talk with clinic staff) to anxiety about painful or uncomfortable medical procedures. Some participants also recounted negative experiences that left lasting impressions. As VW stated,

> When it comes time to be shot with needles, blood tests, and stuff like that … They try to grab me and tie me down and I got up and I left and uh, I never returned to that doctor's office again.

However, participants also recalled strategies that had been helpful for them in reducing or distracting from anxiety and pain. For example, MJ suggested the use of toys or sensory objects to help with anxiety during medical procedures, noting that ''certain textured objects [can] either calm someone down, or it can distract them from some of the procedural things.'' HN found it helpful when providers used humor or conversation to distract him from pain or procedures:

> My doctor … jokes with me a lot to keep me smiling and focused because I'm afraid of needles and things like that … He keeps me calm so I don't have to, uh, panic or have an, have an attack … He distracts me … He starts talking to me and I'm looking at him in the face and then the lady comes in really fast and I don't even know I got hit with a needle. (HN)

Another aspect of the clinic experience that was salient to many participants was the issue of *wait time and visit length*. Overall, there was consensus that lengthy wait times in the waiting room or clinic room were aversive, as was expressed by one participant: ''One thing that's always been a problem with doctors is they take a long time to, uh, not only call your name but also to arrive in the room where you're waiting for them'' (MH). However, visits with the provider that seemed rushed or too brief did not allow adequate time for the participants to express their needs and process information. KR noticed that ''they like to rush you, like they're on a time limit of like 15 minutes or so.'' Another participant explained how feeling rushed can affect the quality of her health care:

> An issue that I have with healthcare is … not feeling like … my concerns are valid enough to mention to the doctor, especially because they always seem so rushed. And so like I'll have things that are bothering me, even if it's just like a little mole or something … Because they rushed so much, sometimes I still planned to say something, but then I, I forget because I'm just flustered by how quickly everything is going and then after the appointment, I'm like, ''ugh.'' (AH)

### *Theme 3: Provider knowledge and practices affect health care experiences*

In addition to system- and practice-level factors, participants also noted provider-level factors that affect their overall health care experiences. In response to questions about *provider knowledge of autism*, many participants lacked confidence in their provider's autism knowledge and expertise, and only a few thought that their providers knew a lot about autism. Some noted that this lack of knowledge contributed to diagnostic delays and other negative interactions with providers. Several participants observed that providers needed a greater understanding of the full autism spectrum. For example, as described by KR, many providers are ''under [the] assumption'' that a patient is neurotypical because of ''only knowing severe cases.'' Similarly, SZ recounted an experience in which her diagnosis was dismissed due to these misconceptions:

> With the autism part, one doctor was … ''You don't seem autistic, you seem fine. You are, you know, you came in here, you brought yourself here'' so I think … that doctor was thinking about … the stereotypical stuff. (SZ)

Participants also perceived this lack of knowledge to be detrimental to overall quality of care. For example, BP observed that:

> [Providers should know] that one size does not fit all, for lack of a better term … I mean, we're not so much like snowflakes as we are like lottery scratchers … What works for one patient isn't necessarily going to work for all of them. (BP)

In a second subtheme, participants almost universally remarked upon the importance of *provider rapport* for successful health care experiences. When participants felt that their providers demonstrated kindness, ''understanding,'' and a genuine interest in them, their health care interactions and experiences were described as being much more positive and helpful. TF appreciated that his health care providers are ''pretty good at engaging in small talk and asking about how things are going,'' and explained that this ''tends to help make things a little less anxious and awkward'' for him. JR specifically remarked upon how his provider effectively incorporates his interests into the visit:

> He also takes an interest in what I'm doing … I'm a big reader, and so every time I come into his office, I bring a book with me and every time he asks, ''What are you reading?'' … he takes care to record the names of the books I'm reading … and I think that's one of my best experiences with healthcare, because that makes me feel really good. (JR)

Several participants also expressed a strong desire to be able to work with a consistent provider who is trusted and familiar. In fact, participants who received care from consistent providers described the most positive experiences. LY noted that he feels ''comfortable'' with his doctor because he is ''familiar with'' him; and EC also noted that she is ''pretty happy'' that she ''get[s] to see the same doctor.'' DC described similar feelings:

> I like him because I've known him a long time, now … So he's not a stranger to me … Yeah. I always see that same doctor 'cause I don't want no more doctors … One time they had another doctor in there, and I wouldn't see him. I said I don't want to see that doctor. That's not my doctor.

A third subtheme focused on *provider communication during health care visits* that affect autistic adults' overall health care experiences. Regarding negative experiences, some participants expressed a need for more time to process information or a desire for simpler explanations from providers. For example, JR explained:

> When I go the doctor's offices and they've shared information with me, like calorie counting or some such, I had trouble like, thinking in my head and getting a good handle on what they were talking about. (JR)

Other participants reported that they often have trouble expressing or explaining symptoms and that their providers are not able to understand what they are communicating. TF explained that he has ''issues sort of explaining what's, um, wrong'' and added that ''it's sort of like a game of charades half the time.'' Participants saw this as both frustrating and undermining the ability to communicate health care needs and participate in the decision-making process, as noted by KR:

> [I] had problems like, communicating a decision … And a lot of times the doctors would just interpret it as, like, me not being ready for like, a surgery, or some kind of treatment … just because … I couldn't get all the thoughts in my head to be able to verbalize it. (KR)

Participants also offered suggestions for how providers might improve their communication with autistic patients. For example, some noted that using more specific prompts and asking follow-up questions may help them remember to report certain symptoms.

> They'd probably have to ask certain questions that really, um, opened up the conversation a bit. Because sometimes I have difficulty self-reporting my symptoms, because I don't have the exact language to express what I mean. (MJ)
>
> I have issues sometimes remembering like, um, when I'm sick or something … So I don't really remember like a hot flashes or something. Um, when doctors mentioned like examples of things that might be related, it sort of jogs your memory on it. (TF)

A final provider-related theme focused specifically on *patient–provider partnership* practices and strategies that affect health care decision-making and treatment adherence. Many participants remarked specifically on how effectively providers navigate the process of balancing health care independence and caregiver involvement. In some cases, providers' tendency to defer to parents or caregivers in treatment decision-making rather than speaking directly to the individual was seen as minimizing of the person's health care independence. SZ observed: ''I think that's one thing that doctors need to keep in mind is that, you know, if the person has a means of communication, they should be communicating.''

Other participants appreciated when providers involved and engaged their parents in clinic visits. In these cases, participants saw caregiver involvement as supportive and helpful for ensuring that health care information was effectively communicated and understood. JC described the most positive health care experiences as times when ''they let my mom come in the room with me'' because it ''makes me more comfortable.'' DC expressed similar feelings, noting: ''I do talk to them, but I like my mom there so she can tell them whatever they wanna know.'' EC also observed that having her parents accompany her to appointments is ''kinda helpful'' because she sometimes gets ''frustrated with all the information.''

Relatedly, participants also reflected on patient–provider partnership strategies that are more or less helpful in facilitating their success with following through on treatment recommendations. Some participants remarked on their difficulty remembering or complying with diet or medication recommendations. Others gave suggestions that ranged from ''persuasion'' to reminders and other strategies to help with compliance at home (such as written summaries, or home-based assistance). For example, KR observed that ''you get a lot of information dropped on you very quickly and if you aren't familiar with the topics that are being discussed then you'll only retain a fraction of it.''

To address this issue, he recommended ''summarizing appointments with written language that people can look back over, um, at the end of those appointments to … something that is personalized to like what exactly was talked about that day.'' He felt that this approach would help patients ''be more compliant with the recommendations and things like that.'' JR also emphasized the importance of a personalized approach, adding that fostering motivation to change requires more than information sharing:

> I wish doctors would talk about the emotional aspect of how to actually give a darn about my health and, you know, why I should, rather than just give information to me, some of which, as I said, I can't understand. (JR)

Other participants expressed a need for additional assistance in between visits to help with adherence to the treatment plan. For example, VW stated: ''I think that it's really important that the doctors show that, you know, that they communicate with us a little more … maybe they should have some monthly care provider that comes and checks on us once a month, or maybe every two weeks … [for example] what time I need to be taking my medicine.'' He further described worries about being independent with his health care regimen: ''my parents are getting old and so like, when they pass away, who's gonna tell me when to take this medicine, if I don't get it, like … I'm just worried that they'll pass away and I'll stop taking my medicine and I'll have an episode, you know.''

## Discussion

Many autistic adults experience significant unmet health care needs.[2,7] The current study was conducted to better understand the perspectives of autistic adults regarding their health care experiences, preferences, and suggestions. Overall, the results are consistent with other recent research[22,23,31–33] and revealed new findings that extend our understanding of health care experiences. Our findings revealed that system-level, provider-level, and patient-level factors contribute both separately and jointly to autistic adults' health care experiences. In particular, interactions between provider-level factors (such as knowledge, skill, and understanding) and the specific needs of individual patients (such as sensory and communication preferences) had a significant impact on aspects of the dyadic patient–provider relationship and on autistic adults' satisfaction with care.

The results provided convergent evidence that many aspects of the U.S. health care system make it difficult for autistic individuals to obtain services. For example, high costs and variability in insurance coverage limit their access to services or preferred providers (particularly specialists and mental health providers). This barrier is not unique to the autistic population,[42,43] as noted by one participant through the member checking process. However, autistic adults often have complex co-occurring conditions that require care from multiple health care specialists.[4–8]

The additive costs of these primary and specialty care services contribute to even greater financial burden, forcing difficult health care decisions that are driven more by cost than need. For many autistic adults, these costs may be prohibitive due to high rates of unemployment and underemployment.[44,45] It should be noted that this study was conducted in the United States. Given that health care costs and systems vary internationally, these specific findings may not be generalizable to the experiences of autistic adults in other countries.

Even when participants were able to afford services, they reported other barriers that made it difficult to receive necessary care. Getting to and from appointments can be challenging, costly, or anxiety-provoking for autistic adults, many of whom do not drive a vehicle or experience difficulties driving and accessing public transportation.[46] For some autistic adults, more easily accessible medical transportation options would be very helpful. Telehealth options could also reduce transportation-related barriers for health care visits that do not require physical contact.[47] The process of getting an appointment is also daunting for many autistic adults. Consistent with other literature,[48–50] some participants noted that communication challenges make it difficult for them to navigate appointment scheduling processes. Health care clinics could address these concerns by offering multiple options for scheduling, including online or electronic booking options. Simplifying, reducing, or offering assistance with pre-visit ''paperwork'' requirements would also be helpful for many autistic individuals.

After primary care is established with a provider, our results underscored the importance of continuity of care for autistic adults. This key aspect of care is also highly related to patient satisfaction and improved health care outcomes in the general population.[51,52] Having a sustained relationship with a provider has been shown to improve trust, familiarity, and patient–provider communication in other patient populations,[51,53,54] and our findings indicate that this may be particularly true for autistic patients. Beyond the interpersonal familiarity that comes from a consistent patient–provider relationship, when providers get to know the autistic person over several visits, they learn much more about that person's communication style, needs for accommodations, and medical history. This, in turn, may help ensure more successful and less anxiety-provoking clinical encounters.

Relatedly, our findings indicate that aspects of the clinic environment and clinical procedures greatly affect autistic adults' comfort and overall health care experiences. Participants' desires for accommodations to address sensory needs and anxiety were particularly striking. Prior research has found that the need for sameness and sensory sensitivity are linked to anxiety among autistic adults,[55] suggesting that clinical visits may be especially challenging due to the likelihood of unexpected and uncomfortable procedures and overstimulating environments. Many of the strategies participants found helpful require minimal resources or effort on the part of clinic staff (e.g., allowing patients to wait in a separate space rather than a crowded waiting room).

Depending on the patient's preferences, other strategies may be helpful and easy to implement, such as using humor or conversation to distract from painful procedures. The desire for visits that do not feel as ''rushed'' among autistic patients is consistent with patient-oriented outcomes research findings that spending adequate time with patients is a key patient priority.[56] Clinics could address this in a variety of ways, ranging from pre-visit planning to gather information and assist with agenda-setting,[57] to more flexibility with scheduling to allow for longer visits when needed.

Provider-level factors also emerged as being centrally important to overall health care experiences for autistic adults. At a basic level, participants who viewed their providers as being knowledgeable about autism appeared to demonstrate more trust in their providers and the quality of their care. Participants also expressed the importance of provider knowledge and understanding of the heterogeneity of autism. Similarly, participants expressed that positive patient–provider interactions, communication, and mutual understanding were important for both patient comfort and for successful outcomes. This finding is consistent with the views expressed by autistic adults regarding their communication preferences[48] and suggests a need for person-centered health care practices that respect and take into account the unique social and communication needs and preferences of each patient.[26]

The results also highlight the importance of effective patient–provider partnerships, reflecting the interaction between both provider- and patient-level factors and the importance of an individualized approach to care. Beyond legal guardianship considerations,[58] providers should be mindful that many autistic adults feel more comfortable when a supporter accompanies them to visits, whereas others may prefer to be entirely independent. Even when caregivers are present, the patient should be at the center of discussions about their health care and the decision-making process. In fact, prior research has found that patients are more likely to comply with provider suggestions when they have understood treatment options and been part of the discussion and decision-making.[59] Our results also indicate that some autistic adults would benefit from additional support in following through on health care recommendations, such as written summaries or regular check-ins.

Recent efforts to develop tools to improve primary care for autistic adults offer many strategies that address the needs expressed by participants in this study, including the AASPIRE Healthcare Toolkit,[27] the UK Royal College of General Practitioners Autistic Spectrum Disorders Toolkit,[24] and other online resources.[24,50] Tools such as these hold promise for empowering patients and their providers with additional strategies for improving health care visits. Our findings also suggest that efforts are needed to increase autism awareness, knowledge, and acceptance among all health care providers, so that the onus is not on the patient to educate their providers or to shop around until they find a primary care provider who is knowledgeable about autism.

There is growing evidence that technology-based training models that include autistic adults on the training team, such as ECHO Autism, may be effective in improving primary care providers' knowledge and self-efficacy in caring for autistic patients.[60] Practice guidelines may also be helpful in promoting widespread improvements in care. Examples of this include the National Institute for Health and Care Excellence (NICE) Autism Spectrum Disorder in Adults: Diagnosis and Management Clinical Guideline.[61]

The study has several limitations that should be noted. First, our findings are based on a small sample and may not necessarily generalize to the larger population of autistic adults. However, our sample size was well within the range deemed appropriate for the qualitative methods used within this study.[35] It is also important to note that qualitative research does not attempt to develop generalizable findings, but rather to develop an in-depth understanding of a particular phenomenon. Although we did not exclude individuals with intellectual disabilities, the interview process may have precluded adults with significant cognitive or language difficulties from participating. Similarly, our sample was limited to adults who had been diagnosed with autism, so our findings may not reflect the experiences of autistic adults who have experienced diagnostic barriers.

In addition, the study sample had relatively limited racial and ethnic diversity and was relatively young. Future research with larger and more diverse samples is needed to more fully understand the perspectives of autistic individuals across a range of identities, including race, ethnicity, language, gender, sexuality, age, and support needs. Furthermore, future research should consider intersectional identities and how they may impact health care access and experiences. For example, the experiences of transgender or nonbinary autistic adults may be different from the experiences of those who are cisgender. Finally, the current study was conducted by non-autistic (allistic) researchers. Future studies should seek to include autistic individuals as members of the research team, in line with Community Based Participatory Action Research principles and frameworks.

Despite the limitations of this study, these results add to a growing body of literature showing that autistic adults face many barriers in accessing appropriate health care services from providers who are knowledgeable and accepting of autism. These findings suggest that improvements to the health care system and additional supports for both patients and providers are needed to enhance overall health care quality and satisfaction for this vulnerable patient population.

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## Authorship Confirmation Statement

M.O.M. and B.A.M. designed and conceptualized the study. M.O.M. oversaw data collection, conducted the analyses, contributed to interpretation of results, and drafted the initial article. E.S. and A.H. participated in coordination, data collection, and qualitative data analysis, and critically reviewed and revised the article. N.C.-Z. contributed to study design and qualitative data analysis, and critically reviewed and revised the article. K.S. and B.A.M. contributed to interpretation of results and critically reviewed and revised the article. All authors read and approved the final article.

## Disclaimer

Opinions, interpretations, conclusions, and recommendations are those of the authors and are not necessarily endorsed by the Department of Defense.

## Author Disclosure Statement

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## Supplementary Material

Supplementary Data

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