

“They looked at me as a person, not just a diagnosis”: A qualitative study of patient and parent satisfaction with a specialized primary care clinic for autistic adults

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Scientific Abstract

Background: Autistic adults have complex physical and mental healthcare needs that necessitate specialized approaches to healthcare. One promising approach is to embed providers with specialized training or specialty clinics for autistic adults within general primary care facilities. We previously found that autistic adults who received their healthcare through one specialty clinic designed with and for autistic adults had better continuity of care and more preventive service utilization than national samples of autistic adults.

Objective: To characterize factors that increased or decreased satisfaction with healthcare received through a specialty clinic for autistic adults.

Methods: We conducted 30-60-minute semi-structured interviews with autistic adults (N=9) and parents of autistic adults (N=12). We conducted an inductive thematic analysis, using a phenomenological approach.

Results: Factors that increased participants' satisfaction included: (1) receiving personalized care from the provider; (2) spending quality time with the provider; and (3) having strong, positive patient-provider relationships. Factors that decreased participants' satisfaction included: (1) lack of access to services due to scarcity of trained providers; (2) difficulty at times communicating with the provider; and (3) system-level barriers such as policies, practices, or procedures.

Conclusion: Our findings highlight the importance of providers using personalized approaches to care that meet patients' sensory and communication needs and spending quality time with patients to establish strong, positive patient-provider relationships. Our findings also underscore the critical scarcity of healthcare providers who are trained to deliver care for the growing population of autistic adults.

Lay Abstract

Why was this study done?

Healthcare clinics specifically designed for autistic adults could better support this group's healthcare needs. A past study found autistic adults who got their healthcare from a specific clinic were more satisfied with their care and had more consistent care than national samples of autistic adults. We did this study to understand what made autistic adults or their parents more or less satisfied with the care they got from this specific clinic.

What did the researchers do?

We based our study in a specific clinic for autistic adults in the Midwestern United States, which opened in 2014. We interviewed 9 autistic adults and 12 parents of autistic adults who got healthcare at this clinic. We looked for common themes in the interviews.

What were the results of the study?

Autistic adults and parents liked when providers customized care around sensory and communication needs (e.g., asking before touching, using visual aids to explain steps). They also liked when the provider (1) made sure they felt heard and not rushed; and (2) developed strong, positive relationships with them by being personable, friendly, understanding, and welcoming. Autistic adults and parents wanted mental health services at the clinic. Sometimes, autistic adults said it was hard to communicate their feelings during healthcare visits. They felt this made it harder to have their needs met. Autistic adults wanted providers to use more realistic pictures to explain things in ways that are respectful of their age and communication skills. Autistic adults often needed flexibility for how their healthcare visits were scheduled and handled but sometimes this flexibility was not available. For example, sometimes autistic adults needed to cancel or change the appointment on the day of the visit, but the clinic required at least 24 hours' notice for visit changes or cancellations.

What do these findings add to what was already known?

There is growing evidence that specific clinics for autistic adults can improve healthcare experiences. Our findings add examples of things healthcare providers can do to improve autistic adults' healthcare experiences, like meeting sensory and communication needs and making sure autistic adults feel heard and not rushed.

What are potential weaknesses in the study?

We included autistic adults and parents from a single clinic who could tell us their ideas by talking or writing. We interviewed more parents than autistic adults. Autistic adults and parents might not have told us everything that makes them less satisfied. We did not include community members who are autistic adults or parents of autistic adults as members of our study team.

How will these findings help autistic adults now or in the future?

Our findings may help people understand how to improve healthcare for autistic adults. For example, healthcare providers can use our findings to deliver better care for autistic adults by customizing care, making sure patients feel heard and not rushed, and developing strong relationships with patients and parents.

Introduction

Patient satisfaction is a commonly used indicator for healthcare quality and currently affects reimbursement rates for healthcare services in the United States. Among other clinical populations, some studies have shown that patient satisfaction is linked with improved health outcomes, like fewer emergency department visits and better mental and physical health,¹ while others have not.^{2,3} In general, however, patients who are more satisfied are more likely to follow through with a plan of care and are less likely to change providers.^{4,5}

Autistic adults often experience poor satisfaction with the healthcare they receive.⁶ Autistic adults' satisfaction with care is likely influenced by a set of unique barriers to healthcare. For example, autistic adults often have sensory needs that make accessing and engaging in healthcare more difficult.⁷ Some autistic adults may need more time to process verbally-delivered information during healthcare visits⁸ or may need to bypass busy, noisy waiting rooms due to sensory sensitivities.⁹ When these sensory needs are unaddressed, autistic adults have reported feeling disoriented and having a more difficult time engaging with the provider during the visit.¹⁰

Additionally, autistic adults often report difficulty communicating with healthcare providers.¹⁰ There are characteristics of both autistic adults and providers that can make effective communication challenging in healthcare settings. For example, autistic adults have reported that difficulty with body awareness can make it challenging to describe and differentiate physical symptoms (e.g., shooting pain vs. dull ache).¹⁰ At the provider level, a major barrier is the lack of autism-specific training,¹¹ which results in a workforce of healthcare providers who have: limited knowledge about autistic adults' needs; low self-efficacy in delivering care for autistic adults; and a lack of openness to providing accommodations for the communication and sensory needs of autistic adults.⁹⁻¹¹

Given the national emphasis on patient experience, and that a priority area for autism research is to improve the availability and accessibility of services across the lifespan,¹² it is important to develop and test models of healthcare delivery that may be better suited to meet autistic adults' needs.¹³ One approach that may be effective at meeting the needs of autistic adults is to embed providers with specialized training or specialty clinics for autistic adults within general primary care facilities. Among other clinical populations, the co-location of specialized care within primary care settings has been linked with greater patient and provider

satisfaction¹⁴ as well as improved health outcomes, such as fewer emergency department visits.¹⁵ In our prior work, we found that autistic adults who received their healthcare through one primary-care embedded, specialized clinic designed with and for autistic adults had: (1) significantly higher levels of satisfaction with care;¹⁶ (2) better continuity of care;¹⁷ and (3) greater preventive care utilization¹⁸ than national samples of autistic adults. The purpose of the present study was to add qualitative context to our prior quantitative work by characterizing factors that increased or decreased satisfaction with care among autistic adults and parents of autistic adults who receive care through this specialized clinic.

Methods

Study Design and Setting

We used a phenomenological approach, which describes participants' lived experiences.¹⁹ We aimed to characterize factors that increased or decreased satisfaction with healthcare among autistic adults and parents of autistic adults who received care through a specialized autism clinic called the Center for Autism Services and Transition (CAST). While CAST has been described in detail elsewhere,^{9,18} we provide a brief overview here. CAST is located in a suburban area of Columbus, Ohio, USA and is embedded in a larger primary care clinic. CAST differs from other healthcare clinics in that this clinic offers accommodations to care to better meet patients' sensory and communication needs and all CAST providers have extensive expertise caring for autistic youth and adults.

Participants

Participants constituted a subset of individuals who completed a self-administered survey on their experiences at CAST. All autistic adults who received medical care through CAST for at least 1 year, were at least 18 years of age, and could provide informed consent were eligible for participation in the survey. Whenever possible, we recruited the autistic adult patient to participate in the study themselves. Parents were offered participation if the patient was unable to provide informed consent and participate in study tasks, per parent report. The last item in the survey asked participants if they would be willing to be contacted for a follow-up interview. Additional details about the survey recruitment methods and content can be found in our prior publication.¹⁶

Of the 113 survey participants, 21 autistic adults and 60 parents agreed to be contacted for interviews. We contacted all autistic adults and parents who indicated willingness to be interviewed by email and/or phone

calls to schedule the interview. All individuals who responded to our emails and/or phone calls were interviewed. Participation in patient-parent dyads was not required. We completed interviews with N=9 autistic adults and N=12 parents. Although our final sample represents a minority of individuals who initially agreed to be contacted for interviews (26%), we felt that we achieved saturation in our themes.

Procedures

We conducted a 30-60-minute semi-structured interview with each participant. Interviews were audio recorded and later transcribed verbatim. Interview guides included primary questions, probing follow-up questions, and prompts. We designed the interview guides to elicit additional information about items addressed in the survey to add context and depth to quantitative findings. Questions included: What was your most recent experience at CAST like? In what ways have you been satisfied with your experience at CAST? In what ways have you been dissatisfied?

All parents (N=12) and a majority of autistic adults (N=7) completed interviews over the telephone, but two autistic adults chose to participate via email. For individuals who chose to participate via email, BH and the participant scheduled a time where they could both be available for an email exchange. The email correspondence functioned like a chat room, with the interviewer asking a single question and waiting for a response before asking another question. BH conducted all of the interviews and took real-time notes. All autistic adults and parents received \$25 Visa eGift cards for their participation in the interview.

Data Analysis

In our prior online survey, participants provided basic demographic information including their gender, age, race/ ethnicity, and amount of time they (or their adult child) have been receiving medical care through CAST. We analyzed the demographic information of the interview participants with descriptive statistics. We conducted a semantic-level, inductive thematic analysis of interview transcripts using a post-positivist paradigm. Two researchers (BH and LH) iteratively identified codes and grouped them into facilitators or barriers in NVivo.²¹ The researchers achieved at least 90% agreement on all codes.

Strategies to Achieve Trustworthiness

Trustworthiness is the extent to which the findings are an accurate representation of the phenomenon being studied.²² To enhance trustworthiness, we had two study team members independently code the data and achieve consensus (investigator triangulation), only included final themes that were present in at least

30% of the interviews (checking for representativeness), and sent participants a 1-page results summary for feedback (member checking). Participants were asked to rate the extent to which the summary accurately reflected their experiences on a 0-10 scale (0="not at all"; 10="completely") and comment on our findings.

Researcher Positionality. We also recognize that the research process and our interpretations are contextualized by our backgrounds. BH is an early career researcher who led this work as part of a career development award. She completed graduate-level courses on qualitative research and worked closely with two mentors (AD, JG) with qualitative expertise. Her interpretations are framed by her background as a clinician-scientist who draws from real-world experiences as an Occupational Therapist to inform her research questions and directions. As a clinician, she worked with children, adolescents, and young adults with various developmental disabilities, including autism. As a health services researcher, BH's body of work seeks to improve healthcare delivery and health outcomes for autistic adults and other clinical populations. CH is the founder and medical director of CAST; to minimize this potential source of bias, CH was not involved in data collection or analysis. Autistic individuals were not involved in the design or implementation of this study.

Ethical Approval

The Institutional Review Board of The Ohio State University reviewed and approved this study (Protocol Number: 2019B0436).

Results

Table 1 summarizes the demographic information of the interview participants, which included only one patient-parent dyad. Table 2 summarizes the facilitators and barriers to satisfaction described by participants.

Table 1: Demographic characteristics

	Autistic Adults (self-report) N=9	Parents ^a N=12	Autistic Adults (parent report) N=11 ^b
Gender, N (%)			
Male	4 (44.4)	2 (16.7)	9 (81.8)
Female	4 (44.4)	10 (83.3)	2 (18.2)
Non-binary	1 (11.1)	0 (0.0)	0 (0.0)
Mean years of age \pm SD (range)	28.3 \pm 4.1 (24-36)	53.2 \pm 3.5 (47-59)	23.0 \pm 3.5 (18-30)
Race/Ethnicity, N (%)			
White, Non-Hispanic	7 (77.8)	9 (75.0)	8 (72.7)
Black, Non-Hispanic	1 (11.1)	3 (35.0)	2 (18.2)
> 1 Race	1 (11.1)	0 (0.0)	1 (9.1)
Highest level of education			
< High school diploma or equivalent	0 (0.0)	0 (0.0)	3 (27.3)
High school diploma or equivalent	2 (22.2)	1 (8.3)	8 (72.7)
Some college	3 (33.3)	1 (8.3)	0 (0.0)
Associate degree	2 (22.2)	1 (8.3)	0 (0.0)
Bachelor's degree	2 (22.2)	7 (8.3)	0 (0.0)
Graduate degree or higher	0 (0.0)	1 (8.3)	0 (0.0)
Not reported	0 (0.0)	1 (8.3)	0 (0.0)
Mean years receiving care through CAST (SD)	3.9 (1.8)	N/A	3.3 (1.4)

^a All parents described their relationship with the CAST patient they support as “parent (legal or biological).”

^b Note there was one patient-caregiver dyad that participated in the interview together. That patient's demographic information is included in the autistic adults self-report column.

Table 2: Barriers and facilitators to satisfaction with healthcare among autistic adults and their caregivers

Theme	Description	Representative Quotes
<i>Facilitators to satisfaction</i>		
Personalized care	Providers made personalized accommodations to care to increase patients' comfort and understanding, including adaptations to meet patients' sensory and communication needs	<p>"The doctor is more aware of things like asking before touching, which a lot of other physicians are not really aware of (laughs) to do" – <i>Autistic Adult</i></p> <p>"They will say things in a way that I could understand, show me visuals and show me what was the next step for me." – <i>Autistic Adult</i></p>
Quality time with the provider	Participants felt they spent a short amount of time waiting and had longer face-to-face time with the provider. This may have been due to feeling heard by the provider or having the provider's full attention.	<p>"We were brought in very quickly to one of the rooms to wait for [Dr. Name] and they came in shortly after." – <i>Parent</i></p> <p>"They make time for questions. They come in the room, they're never rushed." – <i>Autistic Adult</i></p>
Strong, positive relationships	Providers had a positive demeanor and developed rapport with patients and parents.	"I feel they put in an extra effort to double check that I'm doing alright or that there might be an extra thing on my mind." – <i>Autistic Adult</i>
<i>Barriers to satisfaction</i>		
Lack of access to services	Patients have trouble getting the healthcare services they need or want, largely due to too few providers who are trained to care for autistic adults	<p>"I have recently experienced a large difficulty in getting an appointment with my doctor at all..." – <i>Autistic Adult</i></p> <p>"We were contemplating getting him a counselor and, at that time, um, there wasn't a counselor there at CAST." – <i>Parent</i></p>
Difficulty communicating	Difficulty patients face with identifying the way they're feeling and/or difficulty expressing the way they're feeling to others.	<p>"Sometimes I don't unders—don't know always know how to word it or how to describe it." – <i>Autistic Adult</i></p> <p>"He's not always talkative. And his biggest problem is that he has problems expressing himself." – <i>Parent</i></p>
Systemic barriers	Policies, practices, or procedures that created barriers to care or decreased satisfaction	"A lot of times when I call the main number, no one knows what CAST is." – <i>Parent</i>

Note: Patient and physician names have been redacted for confidentiality, and gender-neutral pronouns are used to protect provider identities.

Facilitators to Satisfaction

Personalized care. Patients and parents appreciated their provider's knowledge, experience, and skills when providing personalized care for autistic adults. For example, the doctor may ask before touching a patient with tactile sensitivities and explains things in terms that are easy for patients and parents to understand.

Autistic adults reported that providers customized their communication style to explain things in ways that were easy to understand. For example, one autistic adult said: *"But they'll visually show me, 'Okay. After this, we're gonna do this, and after that's done, we're going to do that.' They're very visual, very, 'What's the next task at hand?' They really know how to work with me."* Similarly, one parent said *"They always check for understanding... They'll just say 'So, [Patient Name], this is what I'd like you to do. Tell me which [medication] you're gonna take in the morning and which one you're gonna take at night.'"*

Participants frequently contrasted their experience with CAST providers to experiences they had with providers who had less experience with autistic adults or were less willing to make accommodations to personalize care. For example, one patient described an experience he had with a non-CAST provider: *"I guess because when I mentioned I have ADD and Asperger's, I'd be one of those people, he wouldn't touch [with] a 22-foot pole, just having those two things together."* When asked to contrast this previous experience to his experiences at CAST, the patient stated: *"I haven't seen that with [my CAST provider], no."* Multiple participants also commented on how difficult it was for them to establish care with an adult provider prior to CAST:

"Before I went to CAST, I went to several other providers. It was very difficult to find somebody that would listen and would be patient enough. I mean, I had a doctor that basically kind of taunted me for not wanting to shake his hand." –Autistic Adult

Quality time with provider. Participants reported that they appreciated spending a short amount of time waiting and having more face-to-face time with the provider. One autistic adult said *"I don't feel like I have to wait in the office as long between going back and then the doctor coming in as some other places."* Another autistic adult said, *"I feel like I spend more time interacting with [the provider]."* Similarly, a parent noted:

"Everything goes really quickly. Unlike some doctor's offices where you have to sit and wait and wait [...] I think that they take their time to really make sure that he's okay versus rushing through the exam so we can get this over with." –Parent

However, we did not measure wait times and visit durations to confirm this with quantitative data. As such, these findings should be interpreted as autistic adults' and parents' perceptions, which may be more reflective of the fact that they felt heard by the provider, rather than objectively having shorter wait times and longer visits. One caregiver said, "*They've been wonderful with my son because, you know, they listen to him.*" Similarly, one autistic adult described her provider as "*having that personality where they want to listen to what you have to say.*"

Strong, positive relationships. Participants appreciated that the providers were personable, friendly, understanding, and welcoming. Providers developed relationships with the autistic adults and parents and were genuinely interested in the patients' wellbeing. One parent said: "*I think their general enthusiasm, you can tell they have a passion for what they do and I think that, kind of, drives the whole entire experience.*"

This theme also may have reflected that patients felt accepted by the provider without encountering stigma. For example, one parent said, "*They never criticize when they talk about my son's weight and I feel comfortable opening up to them.*" This lack of stigma was also described by autistic adults; when recounting her first visit at CAST, one autistic adult said, "*They looked at me as a person, not just a diagnosis. They saw that this is a girl who has autism, but looks at me, I'm 25 years old, very independent.*"

Barriers to Satisfaction

Lack of access to services. Participants sometimes had difficulty getting the healthcare services the patient needed or wanted and recommended: (1) on-site mental health services, and (2) increasing the number of mental health providers equipped to meet autistic adults' needs. Multiple participants reported challenges establishing care with mental health providers in the community who have expertise caring for autistic adults. One parent said that her son's daily life was "*in turmoil*" because a community mental health provider "*prescribed wrong medicines or forget medications*" which "*[threw] the balance off.*" Participants suggested that having mental health care services like psychiatrists or counselors co-located with their primary care would improve their satisfaction, be convenient, and increase access to mental health providers who have expertise working with autistic adults. There was also a lack of access to other services (i.e., social skills training, job skills training, and community integration for autistic adults; social groups for parents), but each was reported by only one participant.

Additionally, participants recommended increasing the number of primary care providers equipped to meet autistic adults' needs. Multiple participants experienced difficulty scheduling timely, convenient appointments for primary care. Multiple participants reported that there were often long wait times before an available appointment. One parent said: *"One time we did try to call it was like a week out to [get in] for a sick visit, so we had to [go] to the urgent care."* An autistic adult said: *"When I went to reschedule [my appointment], the first available appointment of any kind was [two months later]."* Our results suggest a need to increase the number of primary care providers with expertise caring for autistic adults since existing providers' schedules have reached capacity. One autistic adult said they recommended *"get[ting] other doctors trained, because sometimes [the providers at CAST] can't always see them right away."*

Difficulty communicating. Patients and parents occasionally reported that patients experience difficulty identifying their feelings and/or difficulty expressing their feelings to the provider. This can make it more difficult for the provider and patient to work together to meet the patients' needs. Autistic adults recommended and/or used the following strategies to overcome communication barriers: (1) written communication; (2) updated visual prompts; and (3) having conversations about sensitive topics (e.g., sexual or reproductive health, gender identity) with a provider of the same gender. One patient described a way that she and her provider minimize this barrier through written communication:

"If there's something I don't want to talk about or say out loud, I can write it down [...] When my husband died, I wrote it down [...] It was easier to be able to write it out and say it like that." –Autistic Adult

Another autistic adult recommended *"more visual prompts that [are] age-appropriate for all levels of [support needs]"* and are *"more realistic versus like cartoons and emojis"* to help improve patient provider communication. A few autistic adults described feelings of discomfort articulating questions or concerns about sensitive topics (e.g., prostate exams, transitioning to another gender). One autistic adult suggested that:

"Perhaps being able to have a one-on-one private conversation with a doctor of the same gender would be able to help relieve some of the tension [...] That way it may not be seem as embarrassing to myself." –Autistic Adult

Parents often talked about the importance of a team-based approach, incorporating the patient, parent, and provider to overcome communication barriers. One parent said, *"She can communicate, but it's sometimes*

really difficult for her to get all of her thoughts across and she looks to me to help her with that.” Another parent said “I think it's really apparent that [the provider] wants to hear what we have to say. I think it's really important to them” and “I think [the provider] really makes an attempt to talk directly to [my son].”

Systemic barriers. Certain policies, practices, or procedures were reported to decrease patient and parent satisfaction. For example, adhering to a 24-hour cancellation policy was challenging for some individuals.

“I don't know if I'll feel okay until the actual day happens and so it's then really hard, if I need to change an appointment because I understand why doctors want 24 hours' notice or 48 in some cases, but for me, that is not always a reasonable request.” –Autistic Adult

Additionally, while CAST does offer accommodations to bypass the waiting room, participants reported that sometimes this accommodation was not carried out.

“We've got to get her isolated because it's hard waiting [...] It's true I could go up and say, “Hey, we [need to be roomed]” and I do. [...] but I think I don't want to bother the front desk people and be too whiny of a parent, and I wish they would just always know, okay, we need to go get her back.” –Parent

Other participants described frustration and disappointment when trying to call to make an appointment and the scheduler was unfamiliar with what CAST was. One parent noted that this perpetuated feelings of isolation for her:

“A lot of times when I call the main number, no one knows what CAST is. I just think that's a sad thing because, when you're dealing with autism, you feel isolated a lot. And it would be really nice to have people answer the phone go, ‘Oh yeah, the CAST clinic.’ You know what I mean by that? Rather than ‘I don't know what you're talking about.’” –Parent

Member Checking Findings

Ten participants (N=4 autistic adults, N=6 parents) responded to our member checking email. Most (9 of 10 participants) rated our results as an 8 or higher for extent to which our findings reflected their experiences. One parent rated the summary 5/10, commenting “[My son] has not experienced lack of access, difficulty communicating or the system level barriers. We have truly had positive experiences with CAST and will continue to use them as [my son]'s primary care.” This may have reflected a concern that areas identified as barriers to satisfaction would be perceived to overshadow the strengths of CAST that contribute to high satisfaction with care. For example, even among individuals who rated the summary of findings as highly

reflective of their experiences, one parent commented: “*Any negatives in no way outweigh the positives; not even close.*”

Discussion

Specialized, patient-centered approaches to primary care are a promising solution to minimizing the widely documented barriers to care experienced by autistic adults.⁷ We described facilitators and barriers to satisfaction with care among autistic adult patients and parents of autistic adults who receive primary care through one primary-care embedded clinic designed with and for autistic adults. While our findings are inherently tied to the specific clinic from which we recruited participants, this study has broader implications for improving the healthcare of autistic adults in other contexts. Our findings indicate that primary care for autistic adults can be improved by: (1) providing personalized care that is tailored for each patient, including meeting sensory and communication needs; (2) spending quality time so that patients feel heard and not rushed; (3) developing strong, positive patient-provider relationships; (4) increasing the number of providers who are willing and able to meet autistic adults’ needs; (5) offering mental health services on-site at the primary care facility; and (6) considering the impact that policies, practices, and procedures may have on the healthcare experience for this population.

To deliver personalized care, providers can use existing resources such as the pre-visit questionnaire developed by CAST⁹ or the personalized accommodation report developed by Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE).²³ These tools increase the providers’ awareness of the patients’ preferences and needs, which will inform the care they deliver during the patient’s visit. Many of the accommodations valued by autistic adults in our study (e.g., provider asking before touching, explaining a procedure before beginning, allowing patients to communicate in writing, etc.) do not require environmental changes or systemic supports. Indeed, we would argue that many of these behaviors, such as explaining procedures and asking before touching, are foundational tenets of patient-centered care²⁴ that should be implemented universally for all patients.

Similarly, there are a number of strategies providers can and should use universally to ensure all patients feel heard. Participants in our study were satisfied that they were given time to ask all of the questions they had, did not feel rushed, felt that they had the provider’s full attention, and were given time to process

verbally communicated information. Prior studies have shown that the provider having a warm demeanor²⁵ and sitting during the visit²⁶ also increase patients' perceived amount of time spent with the provider.

We assert that providing personalized care and ensuring that patients feel heard are necessary precursors for the development of strong, positive patient-provider relationships. The importance of a strong patient-provider relationship is well documented among myriad populations and is correlated with positive patient outcomes like reduced anxiety,²⁷ increased medication adherence,²⁸ and increased engagement in healthcare decisions.²⁹ Participants in our study reported feeling satisfied when their provider was personable, friendly, welcoming, and genuinely interested in the patient's wellbeing. Unfortunately, our results and prior studies^{30,7} highlight that autistic adults often encounter stigma from healthcare providers, which precludes the development of strong, positive patient-provider relationships. We believe this finding speaks to the urgent need for educational programs for current and future providers to reduce misconceptions and stigma about autistic adults.

Current training in autism is severely limited for physicians.^{11,31,32} The lack of training provided to physicians during residency and physicians' lack of knowledge about working with autistic individuals have been identified as the most critical barriers to primary care for autistic adults.¹¹ CAST providers obtained expertise through educational sessions with developmental and behavioral pediatricians and psychiatrists with experience caring for autistic individuals as well as regular contact with autistic adults and parents. Currently, however, there are no fellowships or formal training programs in the United States that are focused on teaching physicians how to provide care for autistic adults or adults with developmental disabilities. To address this need, there have been recent initiatives to develop trainings for current and future healthcare providers. For example, Extension for Community Healthcare Outcomes (ECHO) Autism Transition³³ is a training (consisting of didactic lessons and expert coaching sessions) that prepares existing healthcare providers to transition autistic patients from pediatric to adult healthcare systems. However, trainings for existing providers may only be effective for motivated individuals who self-select to increase their skills for caring for autistic individuals. Other approaches, such as trainings designed to be a required component of medical student curricula³⁴ may be more effective at reaching a broader audience of future healthcare providers.

In addition to trainings for future primary care providers, there is an urgent need to build the capacity of mental health providers to deliver high-quality, patient-centered care for autistic adults.³⁵ Findings from our

study and others^{35,36} indicate that autistic adults often have difficulty identifying and establishing care with mental health providers who willing and able to meet their needs. Participants in our study also expressed a desire for mental health services to be integrated and co-located with their primary care, which has been shown to increase access to mental health care among other populations.^{37,38}

Finally, our results highlight the need to consider systemic factors (policies, practices, procedures) when delivering care through a specialized clinic in a broader primary care setting. For example, specialty clinics will likely share an appointment scheduling system with the primary care setting in which they are embedded. It will be important to provide regular trainings for schedulers to avoid miscommunications and prevent patients/parents from feeling isolated if the scheduler is unfamiliar with the specialty clinic. Additionally, many clinics have a 24-or 48-hour cancellation policy to reduce the risk of patients' not showing up for appointments and to maintain provider productivity by filling the appointment slot with a different patient.³⁹ However, our findings suggest that such a policy may be challenging for autistic adults to adhere to. With recent the increased use of telehealth,⁴⁰ one possible solution that may better meet autistic adults' needs is to offer a telehealth visit in lieu of an in-person visit the patient is cancelling with less than 24 hours' notice.

Limitations

We offered to administer the interview via email to accommodate participants' communication preferences. However, the average length of the email transcripts was only 1/4th the length of phone-based interview transcripts. In future studies, we will provide a list of interview questions ahead of time and consider alternative platforms for written participation that may allow for quicker exchanges (e.g., via text message).

We used a convenience sample of participants who were able to participate in a survey and interview from a single clinic. The unique attributes of CAST may result in findings that are not necessarily generalizable to other contexts. Additionally, due to the use of convenience sampling, autistic adults in this study are not representative of all autistic adults, particularly those with higher support needs. Although we included parents to characterize the experiences of autistic adults for whom standard survey and interview approaches are inaccessible, future work should directly include individuals with higher support needs by holding one-to-one meetings to explain study participation and administer the interview in a way that accommodates their needs.⁴¹ Additionally, while all CAST patients have a community diagnosis of autism, we did not independently verify diagnoses.

More parents participated in this study than autistic adults, which was consistent with the participation rates of the survey study from which interview participants were recruited.¹⁶ However, we included a greater number of quotes from autistic adults to ensure that their experiences were the primary focus of this work.

It is possible that other barriers and facilitators to satisfaction with care exist among individuals who did not participate in this study. Additionally, some barriers may have been missed if participants selectively reported their experiences to not jeopardize their access to services. However, our informed consent process advised participants that their responses would not affect their medical care or relationship with our institution.

Conclusion

We conducted interviews to determine barriers and facilitators to satisfaction with care among patients and parents of patients who received care through one specialized clinic designed with and for autistic adults. Although our findings are inherently tied to the clinic from which participants were recruited, the barriers and facilitators to satisfaction we identified have broader implications for other healthcare providers and systems seeking to better meet the needs of the growing population of autistic adults. For example, our findings highlight the importance of providers using personalized approaches to care that meet patients' sensory and communication needs and spending quality time with patients to establish strong, positive patient-provider relationships. Our findings also underscore the critical scarcity of healthcare providers who are trained to deliver care for the growing population of autistic adults.

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