



Patient and caregiver experiences at a specialized primary care center for autistic adults

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Background: Little is known about the extent to which patient-centered medical homes meet the needs of autistic adults. **Materials & methods:** We conducted a cross-sectional survey of autistic adult patients ($n = 47$) and caregivers of autistic adult patients ($n = 66$) receiving care through one patient-centered medical home specifically designed to meet the needs of this population. We performed *post hoc* comparisons of our results to previously published data from a national sample of autistic adults. **Results:** Participants reported high levels of satisfaction with care, frequent preventive healthcare use and few unmet healthcare needs. Autistic adults in our sample reported significantly higher satisfaction and fewer unmet healthcare needs. **Conclusion:** A patient-centered medical home tailored to the needs of autistic adults is a promising approach to healthcare delivery for meeting this population's needs.

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Each year in the US, nearly 50,000 autistic individuals turn 18 years old [1]. Relative to the general population, autistic adults experience a disproportionately high prevalence of physical and mental health conditions [2,3]. When unaddressed or under-addressed, these conditions increase autistic adults' risk for serious chronic health conditions [3], premature death [4] and excessive healthcare costs [5]. As the number of autistic adults grows at a rapid pace, it is critical that healthcare systems and providers are responsive to and capable of meeting this population's unique needs. Currently, however, autistic adults face multiple barriers to receiving quality patient-centered care in the community. This includes barriers at the: patient level – such as communication skills, sensory sensitivity, information processing and healthcare self-management; provider level – such as lack of knowledge about autism and openness to providing accommodations; and system level – including availability of support and accessibility of facilities [6–8]. These barriers reduce autistic adults' satisfaction with the healthcare they receive [7], and hinder their ability to obtain treatment for physical and mental health conditions such as hypertension and depression, which they experience more frequently than the general population [3].

As a result, there is a nationally-recognized demand for improved healthcare service delivery models to better meet the needs of this growing population [1]. One model of care delivery that has been linked with high satisfaction among caregivers of autistic children and caregivers of children with other developmental disabilities in the US is the patient-centered medical home [9,10]. The patient-centered medical home is a model of healthcare delivery where a primary care provider coordinates a patient's care to ensure that the patient receives healthcare services when and where they need them [11]. For example, a primary care provider may work with specialists to exchange

relevant clinical information about the patient's care in order to provide more efficient, comprehensive care. Primary care medical homes are characterized by: (1) comprehensive care, including a multi-disciplinary team of providers to meet the majority of patients' healthcare needs; (2) patient-centered care, which recognizes patients and families as essential members of the care team; (3) coordination of care across the broader healthcare system; (4) accessible services, such as reduced wait times for urgent needs, extended in-person hours and alternative methods of communication (e.g., via email or telephone); and (5) an emphasis on quality and safety, such as through the use of evidence-based strategies [12].

Evidence suggests that patient-centered medical homes increase satisfaction with care and reduce unmet healthcare needs among caregivers of autistic children through features like longer clinic visits, and providing resource lists to connect parents with other healthcare professionals with expertise in autism [9]. However, there is a paucity of literature on testing the effectiveness of patient-centered medical homes in meeting the healthcare needs of autistic adults [13]. This study addresses this critical gap in the literature by characterizing the experiences of autistic adult patients and caregivers of autistic adult patients at one patient-centered medical home specifically designed to meet the needs of autistic adults [8].

Materials & methods

Study design

We conducted a non-experimental, cross-sectional study of satisfaction with care, perceived unmet healthcare needs, and healthcare utilization using self- and proxy-report data collection methods.

Study setting

In this study, we sought to understand the experiences of patients and caregivers of patients at a local patient-centered medical home specifically designed for autistic adults. This medical home, which is located in a suburban area of a capital city, is part of a larger university-based hospital system. The clinic was founded in 2014 and is supported by a donation from the White Castle Foundation and Bill and Marci Ingram. Similar to other primary care clinics in the USA, this clinic accepts a range of health insurance plans for services rendered; this includes private insurance plans, which are typically obtained through a place of employment or policies that people buy on their own, as well as public insurance funded through government programs like Medicare and Medicaid. However, in contrast to the standard patient-centered medical home, this clinic was designed in partnership with autistic adults and their caregivers to minimize barriers to healthcare access and healthcare delivery [8]. Specifically, this clinic differs from the standard patient-centered medical home in that patients have an initial intake appointment prior to their first medical visit to identify needed accommodations to the standard patient workflow. For example, patients with sensory sensitivity may bypass the waiting room when coming in for medical visits. Patients with high anxiety can stop by the office or watch high-fidelity video models of common procedures (e.g., blood pressure checks) to familiarize themselves with the environment and expectations. Additionally, patients receive medical care from designated primary care physicians with extensive experience working specifically with autistic youth and adults and may meet with a social worker or nurse two- to three-times per year for care coordination.

Participants & procedures

Study participants consisted of a convenience sample of patients and caregivers of patients who received care through a specialized patient-centered medical home designed for autistic adults. All autistic adults who were at least 18 years of age, had been patients at the clinic for at least one year, and could understand study goals and provide informed consent were eligible for inclusion in this study. Autism diagnoses were not verified by our research team, however in order to receive care through this clinic, all patients had a community diagnosis of autism from either a previous healthcare provider or from a school psychologist. Autistic adults needed to correctly answer the following three questions, presented in a multiple-choice format, to demonstrate capacity to provide informed consent: (1) 'Is participation in this study mandatory or voluntary?' (answer: voluntary); (2) 'Will you be paid to participate in this study?' (answer: maybe. I will be entered into a raffle for a US\$100 Visa gift card); (3) and 'I can stop participating in this study at any time' (answer: true).

Whenever possible, we recruited the patient to participate in the study themselves. Primary caregivers were given the option of participating, if the patient was unable to provide informed consent and participate in study tasks (per caregiver report). A primary caregiver is someone who takes primary responsibility for an individual who cannot fully care for themselves; this may be a family member, trained professional or another individual. Specifically,

caregivers were eligible for inclusion, if they: (1) were at least 21 years of age; and (2) the patient for whom they provide care was at least 18 years of age and had been a patient for at least one year.

Participants were recruited using messages through the electronic health record (MyChart messages), emails to the clinic list-serve, waiting room fliers and in-person recruitment at clinic appointments. For MyChart messages and email recruitment, potential participants received a brief study description with a link to the survey site. A total of three messages were sent to each potential participant to maximize our response rate. With regard to clinic recruitment, a study team member (not a clinician at the clinic) approached potential participants in the exam room upon completion of their medical visit with a healthcare provider. Potential participants were given a brief verbal description of the study and a flier. Study team members explicitly stated to all potential participants that study participation was voluntary, could be stopped at any time, and would not impact the patient's care at the clinic in any way. Individuals interested in participating had the option of completing the survey at a later time using the link on the flier or completing the survey in the exam room on a provided iPad. Participants were entered into a raffle to receive one of three US\$100 Visa eGift cards as a token of appreciation for their participation.

Measures

All self-report measures completed by autistic adult participants were validated for use with this population using a community-based participatory research approach [7]. When necessary, the questions were modified in order to have a proxy-report version for caregivers. These modifications are described below. Modified items were not re-validated.

Satisfaction with care

Satisfaction with healthcare provision was quantified using items from an adapted version of the Health Information National Trends Survey [14–16]. Patients rated the extent to which their healthcare provider: gave them time to ask all of their questions; addressed their feelings/emotions; involved them in healthcare decisions; ensured understanding of needed steps for health management; helped them deal with feelings of uncertainty; understood what they were trying to communicate; communicated in a way they understood; and could be trusted to take care of their needs. All items were rated on a 4-point Likert scale, ranging from never to always, where higher scores indicated greater satisfaction.

Caregivers used the same 4-point Likert scale to rate the extent to which the patient's healthcare provider: gave them and/or the patient time to ask all of their questions; addressed the patient's feelings/emotions; involved them and/or the patient in healthcare decisions; ensured the caregiver's understanding of steps needed for the patient's health management; ensured the patient's understanding of steps needed for their own health management; helped them and/or the patient deal with feelings of uncertainty; understood what the caregiver was trying to communicate; understood what the patient was trying to communicate; communicated in a way the caregiver understood; communicated in a way the patient understood; and could be trusted to take care of the patient's needs.

Unmet healthcare needs

We used a single item adapted from the 2002/2003 Joint US Canada Survey [17,18] to measure perceived unmet healthcare needs. Autistic adults answered the question: “*during the past 12 months, there was a time when I felt that I needed the following type of healthcare, but did not receive it.*” Caregivers answered the question “*during the past 12 months, there was a time when I felt that the patient for whom I provide care needed the following type of healthcare, but did not receive it.*” Participants then checked any of six types of healthcare services that they felt they/the patient needed but did not receive, which included: medical care for a physical health problem; mental healthcare or counseling; preventive healthcare (including routine physical examinations); dental care (including dental checkups); prescription medications; and eyeglasses or contact lenses.

Healthcare utilization

Items used to measure healthcare utilization were derived from the 2007 National Health Interview Survey Questionnaire [19]. Participants (self- or proxy-) reported the total number of times the patient visited the emergency department, had an outpatient visit or was hospitalized in the past 12 months. Additionally, participants indicated whether the patient had their blood pressure checked in the last 12 months, had a tetanus vaccination in the last 10 years and had a Papanicolaou (Pap) test/Pap smear in the last 3 years (for female patients only).

Table 1. Demographic characteristics.

Characteristics	Autistic adults (self-report) n = 47	Caregivers n = 66	Autistic adults (caregiver report) n = 66
Gender, n (%)			
– Female	11 (23.4)	53 (80.3)	11 (16.7)
– Male	35 (74.5)	13 (19.7)	55 (83.3)
– Non-binary	1 (2.1)	0 (0.0)	0 (0.0)
Age in years, mean $\pm$ SD	25 $\pm$ 5.4	55 $\pm$ 6.3	25 $\pm$ 5.4
Race/ethnicity, n (%)			
– White, non-Hispanic	41 (87.2)	55 (83.3)	51 (77.3)
– Black, non-Hispanic	4 (8.3)	7 (10.6)	9 (13.6)
– Hispanic	0 (0.0)	2 (3.0)	2 (3.0)
– More than one race	2 (4.3)	2 (3.0)	2 (3.0)
– Other	0 (0.0)	0 (0.0)	2 (3.0)
Highest level of education, n (%)			
– < High school diploma or equivalent	4 (8.3)	0 (0.0)	19 (29.2)
– High school diploma or equivalent	16 (34.0)	7 (10.8)	43 (66.2)
– Some college	12 (25.5)	14 (21.5)	2 (3.1)
– Associate degree	5 (10.6)	4 (6.2)	1 (1.5)
– Bachelor's degree	7 (14.9)	22 (33.8)	0 (0.0)
– Some graduate school	1 (2.1)	6 (9.2)	0 (0.0)
– Graduate degree or higher	2 (4.3)	12 (18.5)	0 (0.0)
– Unknown	0 (0.0)	1 (1.5)	1 (1.5)
Employment status, n (%)			
– Employed full time	10 (21.3)	37 (56.1)	–
– Employed part time	17 (36.2)	14 (21.2)	–
– Not employed	20 (42.6)	8 (12.1)	–
– Retired	0 (0.0)	7 (10.6)	–

Note: "–" indicates question not asked.

Data analysis

Descriptive statistics were used to characterize participant demographic characteristics and study outcomes. Satisfaction with care, unmet healthcare needs and healthcare utilization were analyzed descriptively at the item level. Continuous variables are presented as means and standard deviations, while categorical variables are presented as frequencies and percentages. As a *post hoc* analysis, we compared the response of autistic adults in our sample to published self-report data from a national sample of autistic adults using independent samples t-tests for continuous variables and chi-square tests for categorical variables [7]. Statistical analyses were completed in SAS statistical software, version 9.4.

Ethical approval

The institutional review board reviewed and approved this study (Protocol Number: 2019B0135).

Results

Participant characteristics

Survey sample

A total of 147 unique individuals (n = 69 patients, n = 78 caregivers) responded to the survey and completed a set of questions to screen for study eligibility. From the 147 respondents, 50 patients and 66 caregivers met study inclusion criteria. A total of 47 patients and 66 caregivers completed the survey. Demographic characteristics of participants are provided in Table 1. The majority of patients who completed the survey were male (74.5%), white non-Hispanic (87.2%), employed either full or part time (57.5%), and had completed some college or higher education (57.4%). Caregiver participants were predominately female (80.3%), white non-Hispanic (83.3%), were

Table 2. Satisfaction with healthcare provision among autistic adults and caregivers of autistic adults who receive care through a patient-centered medical home.

Item	Patient self-report (n = 47)	
	Mean $\pm$ SD	Participants responding usually or always, n (%)
Health professionals gave me the chance to ask all the health-related questions I had.	3.9 $\pm$ 0.3 [†]	47 (100.0)
Health professionals gave the attention I needed to my feelings and emotions.	3.9 $\pm$ 0.4 [†]	45 (95.7)
Health professionals involved me in decisions about my healthcare as much as I wanted.	3.7 $\pm$ 0.5 [†]	46 (97.9)
Health professionals made sure I understood the things I needed to do to take care of my health.	3.9 $\pm$ 0.4 [†]	46 (97.9)
Health professionals helped me deal with feelings of uncertainty about my health or healthcare.	3.8 $\pm$ 0.5 [†]	45 (95.7)
Health professionals understood what I was trying to communicate.	3.6 $\pm$ 0.6 [†]	44 (93.6)
Health professionals communicated in a way that I could understand.	3.7 $\pm$ 0.6 [†]	44 (93.6)
I felt I could trust health professionals to take care of my healthcare needs.	3.8 $\pm$ 0.6 [†]	44 (93.6)
Item	Caregiver report (n = 66)	
	Mean $\pm$ SD	Participants responding usually or always, n (%)
Health professionals gave me and/or the patient the chance to ask all the health-related questions we had.	3.9 $\pm$ 0.3	65 (98.5)
Health professionals gave the attention the patient needed to their feelings and emotions.	3.9 $\pm$ 0.4	64 (97.0)
Health professionals involved me and/or the patient in decisions about their healthcare as much as we wanted.	3.9 $\pm$ 0.4	65 (98.5)
Health professionals made sure I understood the things I needed to do to take care of the patient's health.	3.9 $\pm$ 0.4	64 (97.0)
Health professionals made sure the patient understood the things they needed to do to take care of their own health.	3.9 $\pm$ 0.4	63 (95.5)
Health professionals helped me and/or the patient deal with feelings of uncertainty about their health or healthcare.	3.8 $\pm$ 0.5	63 (95.5)
Health professionals understood what I was trying to communicate.	3.9 $\pm$ 0.4	63 (95.5)
Health professionals understood what the patient was trying to communicate.	3.6 $\pm$ 0.6	59 (89.4)
Health professionals communicated in a way that I could understand.	3.9 $\pm$ 0.4	65 (98.5)
Health professionals communicated in a way that the patient could understand.	3.7 $\pm$ 0.6	60 (90.9)
I felt I could trust health professionals to take care of the patient's healthcare needs.	3.9 $\pm$ 0.4	65 (98.5)

[†]Significantly higher ($p < 0.001$) than average scores from a national sample of autistic adults ($n = 209$) as reported by Nicolaidis *et al.* [7].
SD: Standard deviation.

employed full or part time (77.3%), and had completed an Associate degree or higher (68.2%). Caregivers also provided some demographic information about the autistic adult for whom they provide care. On an average, patients whose caregivers completed the survey were 24.6 years of age (standard deviation [SD] = 5.4). Most were male (83.3%), white non-Hispanic (77.3%), and had a high school diploma or equivalent (66.2%).

Comparison group

In a prior study [7], a national sample of 209 autistic adults self-reported their satisfaction with healthcare, unmet healthcare needs, and healthcare utilization. Most autistic adult participants were female (58.4%), white non-Hispanic (85.2%), and had completed some college or higher education (90.0%) [7]. On an average, autistic adults were 37.3 years of age (SD = 12.9 years) [7].

Satisfaction with care

Table 2 provides descriptive information about autistic adult and caregiver satisfaction ratings. Overall, both autistic adults and their caregivers reported high levels of satisfaction with care. Out of a possible 4 points, item-level average ratings ranged from 3.6 to 3.9. The lowest levels of satisfaction were observed for the items “*health professionals understood what I was trying to communicate*” and “*health professionals understood what the patient was trying to communicate*” among patients and caregivers, respectively.

Unmet healthcare needs & healthcare utilization

Descriptive information about patient and caregiver-reported unmet healthcare needs and healthcare utilization is provided in Table 3. The most common unmet healthcare need was for mental health services, as reported by both patients (21.3%) and caregivers (16.7%). According to both patients and caregivers, a majority of patients had their blood pressure checked in the past 12 months and had a tetanus vaccination in the past 10 years. Approximately

Table 3. Unmet healthcare needs and healthcare utilization among autistic adults who receive care through a patient-centered medical home.

	Patient self-report (n = 47)	Caregiver report (n = 66)
Unmet healthcare needs, n (%)		
	During the past 12 months, there was a time when I felt that I needed the following type of healthcare, but did not receive it.	During the past 12 months, there was a time when I felt that the patient for whom I provide care needed the following type of healthcare, but did not receive it
– Medical care for a physical health problem	4 (8.5) [‡]	7 (10.6)
– Mental healthcare or counseling	10 (21.3)	11 (16.7)
– Preventive healthcare (including routine physical examinations)	5 (10.6) [†]	8 (12.1)
– Dental care (including dental checkups)	7 (14.9) [‡]	6 (9.1)
– Prescription medications	5 (10.6)	3 (4.5)
– Eyeglasses or contact lenses	5 (10.6)	6 (9.1)
Patient healthcare utilization, n (%)		
– Blood pressure checked in past year	45 (95.7)	64 (97.0)
– Four or more outpatient visits in past year	12 (25.5)	16 (24.2)
– Hospitalized in past year	4 (8.5)	4 (6.1)
– Emergency department visit in past year	12 (25.5)	17 (25.8)
– Pap test in past 3 years (females only)	6 (54.5)	2 (18.2)
– Tetanus vaccine in past 10 years	33 (77.3)	47 (71.2)

[†]Autistic adults in our sample were significantly less likely ($p < 0.05$) to report having this unmet need compared with a national sample of 209 autistic adults [7].

[‡]Autistic adults in our sample were significantly less likely ($p < 0.01$) to report having this unmet need compared with a national sample of 209 autistic adults [7].

26% of patients visited an emergency department in the past year and 6–9% were hospitalized. The majority of female patients who completed the self-report survey (54.5%) had a Pap test in the last three years. However, among those patients whose caregivers completed the survey, only 18.2% had a Pap test in the past 3 years.

Post hoc comparisons

Our *post hoc* analysis revealed autistic adults in our sample had significantly higher satisfaction with care across all items (Table 2) than the national sample of autistic adults. Additionally, autistic adults in our sample were significantly less likely to report unmet needs (Table 3) for preventive services ($p < 0.05$), physical health conditions ($p < 0.001$), and dental care ($p < 0.001$). Table 3 describes the self-reported healthcare utilization of autistic adults in our study, including blood pressure checks, outpatient visits, hospitalizations, emergency department visits, Pap tests, and tetanus vaccines. Our *post hoc* analysis revealed that our sample did not significantly differ on self-reported healthcare utilization from a national sample of autistic adults.

Discussion

The population of autistic adults is growing at a rapid pace that necessitates the development of informed systems of care, readied and capable of meeting this population's unique health needs [1]. In prior studies, receiving care through a patient-centered medical home has been linked with improved outcomes among general medical populations, with greater patient satisfaction, delivery of preventive care services, and reduced emergency department use [20]. This is the first study, to our knowledge, to characterize the experiences of a population of autistic adult patients receiving care through a specialized patient-centered medical home, a promising model of delivery whereby care is coordinated through a primary care provider. Overall, autistic adult patients and caregivers of autistic adult patients receiving care through a patient-centered medical home reported high levels of satisfaction with care, preventive healthcare use and few unmet healthcare needs. Moreover, our *post hoc* analysis revealed that, relative to published data from national samples of autistic adults [7], autistic adults in our study reported significantly higher levels of satisfaction with care as well as fewer unmet needs for preventive services, physical health conditions, and dental care. These findings suggest that a specialized patient-centered medical home may be a promising approach to healthcare delivery for better meeting the needs of the autistic adult population.

The findings of this study also identify possible opportunities for further improving the experiences of autistic adult patients. First, results revealed the lowest levels of satisfaction with the extent to which healthcare providers

understood what the patient was trying to communicate. This finding is consistent with existing literature, which documents autistic adults' challenges in communicating with healthcare providers [21–23]. Further work is needed to identify effective solutions to facilitate better communication between autistic adults and their healthcare providers. This may include looking into alternate modes of communication (e.g., via written language) or developing provider education programs.

Second, the most commonly reported unmet need was for mental health services. Given the high prevalence of co-occurring mental health conditions among autistic adults [3], it is critical that primary care providers take steps to ensure that patients are connected with community mental healthcare providers who are knowledgeable about autism and can provide quality care for this population. Additionally, having mental healthcare professionals located on-site in the primary care facility may be a beneficial strategy to improve access to mental healthcare and patient mental health outcomes [24].

Last, relative to the general population, in which 78% of women report receiving a Pap test in the past three years [25], the proportion of autistic adult women in this study who received Pap tests is quite low. This finding is consistent with prior literature on underutilization of cervical cancer screenings among autistic adults [26]. While our data do not reveal the reasons for the low utilization of this preventive service, we posit this may be due to factors such as an assumption of sexual inactivity, which would speak to the need to develop provider education opportunities to shift perceptions about sexual health for autistic adults, or behavioral difficulties that may complicate the procedure. Given that there is evidence to suggest that individuals with intellectual and developmental disabilities may be at elevated risk of sexual abuse and sexually transmitted infections [27], the appropriateness of a Pap test may be an important area for healthcare providers to discuss with their patients and/or their patients' caregivers. Further, this discussion may give providers an opportunity to discuss sexual health, a topic that is often unaddressed or under-addressed with women with intellectual and developmental disabilities [28,29].

Limitations

There are a number of limitations to this work. We did not independently verify autism diagnoses for this study. However, all patients at this patient-centered medical home have a community diagnosis of autism from a prior healthcare provider or a school psychologist. We did not verify the self- and proxy-reported healthcare utilization. As such, there may be some recall bias in the results that we presented here. Further, we have no data on individuals who chose not to participate in this study. As a result, we could not determine similarities or differences in the characteristics of individuals who did and did not participate. Due to the myriad recruitment methods utilized, we cannot be sure how many individuals were given an opportunity to participate in the study. As such, we could not calculate a response rate. Patients and caregivers were not required to nor prohibited from participating in dyads. As such, it is possible that in some cases, both a caregiver and the patient completed the survey. However, all efforts were made during in-person recruitment to have the patients participate whenever possible and caregivers were only offered the option of participating in the event that the patient was unable to complete study tasks (per caregiver report).

In our *post hoc* analysis, we used data from a published study [7] rather than prospectively collecting data from a national sample of autistic adults. The autistic adults included in Nicolaidis and colleagues' study (2013) tended to be older (average age 37.3 years) and the majority were female (59%). There is at least some evidence that suggests that autistic adults over the age of 26 are less satisfied with their healthcare than those under the age of 26 [30]. As such, it is possible that underlying differences in demographic characteristics between our sample and that of Nicolaidis and colleagues may have confounded our findings. Other variables that we did not capture in our survey, like health insurance coverage and Autism-Spectrum Quotient (AQ), but were considered by Nicolaidis and colleagues, may also have been confounders. In an effort to maximize response rate and minimize respondent burden, there were some questions that we did not include in order to keep the survey brief. As such, we cannot be certain of the influence of these variables on the differences between our findings and that of Nicolaidis and colleagues. Despite the limitations to our work discussed here, we felt that this *post hoc* analysis was a valuable contribution to the present study by allowing our findings to be interpreted in the context of the healthcare experiences of autistic adults in the US.

Conclusion

In this study, we used self- and proxy-report measures to characterize the experiences of patients receiving care through a patient-centered medical home specifically designed for autistic adults. Our findings suggest that a

specialized patient-centered medical home for autistic adults yielded increased satisfaction with care and reduced unmet healthcare needs for preventive services and physical health conditions, relative to a national sample of autistic adults. Ultimately, patient-centered approaches to primary care delivery may improve health outcomes and reduce rates of premature deaths among autistic adults. Additionally, our findings highlight some potential targets for improvement to maximize quality of care and health outcomes for autistic adults. For example, considering alternate modes of communication, offering mental-health services on-site, and thoroughly addressing sexual health may have contributed to better patient and caregiver experiences and further reduced unmet healthcare needs.

Summary points

- There is an urgent need to identify systems of healthcare delivery that can meet the needs of the growing population of autistic adults.
- One promising approach within the US healthcare system is the patient-centered medical home, which has demonstrated effectiveness and improved satisfaction among other adult diagnostic populations, as well as among children on the autism spectrum.
- Patient-centered medical homes are hallmarked by: comprehensive care; patient-centered care; coordination of care; accessible services; and an emphasis on quality and safety.
- However, to-date, there is limited research that examines the extent to which patient-centered medical homes meet the needs of autistic adults.
- We surveyed patients and caregivers of patients who receive care through a specialized patient-centered medical home specifically designed to meet the needs of autistic adults.
- Relative to published data from national samples of autistic adults, autistic adults in our study reported significantly higher levels of satisfaction with care as well as fewer unmet needs for preventive services, physical health conditions and dental care.
- Our findings also highlighted opportunities for continued improvement, particularly with regard to patient-provider communication, mental health needs and preventive sexual healthcare.
- A specialized patient-centered medical home with knowledgeable physicians and accommodations to the standard patient workflow may be a promising approach to healthcare delivery for better meeting this population's needs.

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No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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- **Contains the data on the comparison sample of autistic adults from across the US and all data collection methods for the comparison sample.**
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