Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting

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Abstract

Little has been reported about how to improve health care access and delivery for adolescents and adults with autism spectrum disorder. To understand the contributions to the health disparities in the autism spectrum disorder population, we conducted two independent research approaches to learn about current medical needs. A retrospective chart review was performed to evaluate medical comorbidities and medication use. A focus group was also created to address barriers faced in providing medical care. Of 126 charts reviewed, 49% (n = 62) had intellectual disability, 49% (n = 62) had attention-deficit hyperactivity disorder, 52% (n = 65) had anxiety, 41% (n = 52) had obesity, 31% (n = 39) with a history of aggressive behavior, 31% (n = 31) had depression, 22% (n = 28) had seizures, and 9% (n = 11) had hypertension. A Medical Regimen Complexity Index score was determined to examine medication use trends in the autism spectrum disorder population. Medical Regimen Complexity Index scores were significantly higher for patients with intellectual disability, patients with seizures, and patients with a history of aggressive behavior. Both the focus group and our pre-visit assessment identified the waiting room and waiting time as barriers to care. Understanding the comorbidities, polypharmacy, and medical barriers should provide a better understanding of the current health care access and delivery needs of adolescents and adults with autism spectrum disorder.

Keywords

adolescents, adults, autism spectrum disorders, health services, medical comorbidity

Introduction

Autism spectrum disorder (ASD) is a range of neurodevelopmental disorders characterized by impairments in social interactions, limited interests, and repetitive behavior (American Psychiatric Association (APA), 2013). The prevalence of adults diagnosed with ASD is rapidly increasing (Van Naarden Braun et al., 2015). As a result, there is an ever-growing population of adults with ASD needing medical care. However, adults with ASD are less likely to have a primary care physician (PCP) and more likely to report unmet medical needs or dissatisfaction with their care (Liptak et al., 2006; Nicolaidis and Raymaker, 2013) than the general population. Additionally, medical providers report lack of comfort caring for adults with ASD (Balogh et al., 2010; Patel and O'Hare, 2010). Even if they have a PCP, adults with ASD are more likely to be hospitalized or visit the emergency room than the general population (Lunsky et al., 2013), suggesting either barriers to access of care and/or barriers to successful

treatment of medical needs in a primary care setting. Little is published on how to improve health care access and delivery for adults with ASD.

In addition, certain common medical conditions have been found to be more prevalent in patients with ASD. For example, past studies show that the prevalence of at least one anxiety disorder among patients with ASD was 39.6% (Van Steensel et al., 2011). Other conditions found to be commonly correlated with the ASD pediatric population include being overweight and obesity (Hill et al., 2015), gastrointestinal (GI) problems (Chaidez et al., 2014), and

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sleep disorders (Kotaal and Broomall, 2012). Less is known about the prevalence of medical comorbidities in adult patients with ASD. Recent work has suggested that the most common medical conditions were found to be seizures, obesity, insomnia, and constipation (Jones et al., 2016). Similarly, seizures (11%–29%), depression (9.7%–17.9%), and attention-deficit hyperactivity disorder (ADHD; 22%–35%) have been reported to occur in higher frequency of adults with ASD than the general population (Fortuna et al., 2016). Additional work is needed to better define the prevalence of comorbidities in this population.

Furthermore, little is known about medication use in adults with ASD. Recent work by Jones et al. (2016) reported high rates of antiepileptic (35%), serotonergic (36%), atypical antipsychotic (34%), benzodiazepines (20%), and first-generation antipsychotic (13%) medications. Additionally, more than half of the patients included in their study were on four or more medications. They found no significant correlation between the frequency of psychotropic medications and common medical conditions such as hypertension, diabetes mellitus, and hyperlipidemia, but did note an increased benzodiazepine use in patients of the ASD population with severe intellectual disability (ID). However, this was done in a population felt to be more severely affected than the general population of people with ASD, so their findings may not be representative of the broader community of patients with ASD.

Medication regimen descriptions using only the quantity of medications prescribed or drug therapy classes also fail to comprehensively identify factors such as dosing frequency and additional usage directions that can impact patient care delivery and outcomes. The complexity of medication regimens has been identified as an improved method to characterize medication use for various populations. Regimen complexity data have been published in the geriatric population (Wimmer et al., 2015), in the hypertension and diabetic population (Rettig et al., 2013), and even the population of geriatric patients with depression (Linnebur et al., 2014). Of note, higher medication regimen complexity of children with ASD has been correlated with better adherence (Logan et al., 2014); however, the complexity of medication regimens in adolescents and adults with ASD has not been examined before this study.

As the adolescent and adult population with ASD continues to grow, it becomes imperative that we look for approaches to better understand the medical needs and desires of these patients and their families, while seeking resolutions and opportunities to overcome barriers to access of care and successful treatments within the primary care setting. This study sought to (1) identify environmental and process barriers to care access in our primary care environment, (2) describe general patient self-identified barriers to medical care, and (3) examine medication use in our adolescent and adult population as potential approaches to recognize and overcome some of the barriers patients with ASD experience.

Methods

The Center for Autism Services and Transition (CAST) at The Ohio State University was created in April 2014 to address the needs of adolescents and adults with ASD as they transition into adult medical settings. CAST functions as a primary care medical home for adolescents and adults with ASD. The medical team currently includes PCPs, a registered nurse focused on care coordination, a social worker, a clinical pharmacist, and a transition coordinator. The CAST Program currently serves approximately 400 individuals with ASD. To address our desired objectives, two independent research approaches were taken to collect data on adolescent and adult patients with ASD. The first was a retrospective chart review to collect data pertinent to office environmental and process barriers as well as medication-related information. The second approach completed was a structured focus group process described below.

Retrospective chart review

Participants. A chart review of all patients who were seen in the CAST clinic at The Ohio State University between April 2014 and April 2015 was conducted. All patients who telephoned to enroll in the CAST clinic during this time period were considered for inclusion. Diagnosis of ASD was confirmed at the time of their visit by review of prior medical and psychological evaluations. Patients who did not attend their initial scheduled visit or who were younger than 15 years of age were excluded from the data collection.

Procedures. A retrospective cross-sectional study was conducted. Information collected from the electronic medical records included demographic data (age, gender, race/ethnicity), vital signs (height, weight, body mass index (BMI)), diagnoses and medical comorbidities, and medications at the time of the initial visit. Also from the medical records we extracted data from our structured pre-assessment visit documentation. Prior to the patient's first office visit at CAST, a standardized pre-visit telephone assessment was completed by either the CAST nurse or transition coordinator. The same set of questions was asked of each patient (see Figure 1). The assessment was designed to identify any barriers to achieving a successful medical visit that may exist. Individuals providing the information included the patient or their primary caregiver. If concerns were raised during the telephone assessment, individualized plans were created by the staff member performing the assessment to overcome these barriers within the existing medical office setting. Data collected from the individualized plans and the initial visit

Name/Age:

Individual completing the assessment:
    -Relationship to patient:

Do you have POA or Guardianship?

Medical Diagnosis:
1. Autism at the age of ***. Who diagnosed him/her?
2.

Has he/she been hospitalized in the last year?

Does he/she have any physical limitations?

Can he/she perform their own ADL's? (hygiene: showering, toileting, etc)

How has he/she reacted in the past to appointments with doctors?

    Has he/she had a blood draw done before?

    How has he/she responded?

IN YOUR OPINION, what do you think is his/her IQ range (select one):
- ☐ Below Average
- ☐ Average
- ☐ Above Average

Communication skills/preference (verbal/nonverbal/other):
- ☐ Verbal
- ☐ Nonverbal
- ☐ Other/ Device?

Does he/she enjoy speaking with others?

Does he/she have behaviors concerning to you?

What triggers his/her anxiety?

Does he/she have a coping skill to deal with this anxiety?

Please provide ideas of what he/she can enjoy in the office setting while waiting.

Does he/she have any special sensory needs or issues? (touch, sounds, lights)

Does anything need to be avoided while in the office?

Figure 1. Pre-visit phone assessment template.

included patient concerns identified during the pre-visit assessment, if the patient needed a unique clinical intervention(s), description of the unique clinical intervention, any outcomes associated with the intervention (i.e. were patients able to tolerate the necessary parts of the clinical visit), and any adverse events that may have occurred at the initial visit.

The pre-visit assessment was completed via the telephone and included information about diagnoses, communication skill level, intelligence quotient (IQ) range (e.g. above, below, normal), previous experiences in medical settings (specifically if any event triggered the patient to struggle in a medical setting), and if the patient had any physical limitation. The IQ range or presence of intellectual disability was based on the patient or caregiver's assessment and was not verified objectively by testing. Any person reporting below normal IQ or providing a reported IQ lower than 70 was considered to have ID for the purposes of this study analysis. Patients and caregivers were also questioned about a history of aggressive behavior. This included both physical aggression and verbal or emotional outbursts. Any mention of physical, verbal, or emotional aggression in either the pre-visit assessment or the documentation from the initial clinical visit was recorded as being positive for aggressive behavior, regardless of whether this was current or prior behavior.

Medication use. Data were collected for medication use by drug therapy category and described as total number of different categories of medications taken daily. In order to more completely examine trends in medication use in the ASD population, a Medical Regimen Complexity Index (MRCI) score was calculated for each patient (George et al., 2004). The MRCI uses number of medications, medication form (e.g. tablet and cream), frequency (e.g. once daily prn and twice daily), and additional directions (e.g. crush tablet and as directed) to calculate an overall score per patient.

As an example, a medication dosed twice daily and administered as a liquid formulation would score a 2 for the liquid form and a 2 for the frequency. The MRCI is a standardized instrument with predefined weighted values that is applied for each drug in the patient's medication regimen. The MRCI score is then determined by summing the individual values for each drug. The score has no upper limit, and as the score increases, the regimen complexity increases. Utilizing this tool allows for a more complete understanding of medication administration and related adherence barriers that might otherwise be overlooked by simply counting the number or drug classes a patient is receiving.

This method has been validated for chronic diseases (Libby et al., 2013) and has been suggested as a method to identify patients who may benefit from medication therapy management (Hirsch et al., 2014).

Statistical analysis. Patient characteristics were summarized as mean and standard deviation for continuous variables and number and percentage for categorical variables. For each comorbidity (ID, seizure, anxiety, depression, aggressive behavior, obesity, ADHD, and hypertension), MRCI scores were compared between patients with and without the comorbidity by Wilcoxon rank-sum tests. Associations between comorbidities and medication types were assessed by chi-square tests. Use of specialized intervention was compared for each comorbidity by chi-square test. All statistical tests were evaluated at the $\alpha = 0.05$ significance level.

Focus group

Additionally, we report findings that were derived through a participatory design research case study (Braun, 2016). A single focus group session was conducted with 10 adults with ASD, using co-design methods (Sanders et al., 2010). The aim of the focus group was to understand the clinic experience from the perspective of the patient while allowing them to take part in exploring ideas (using hands-on materials) to overcome challenges and unmet needs. The nature of the session was conversational and focused around gathering qualitative data regarding the patients' experiences within medical clinics. Findings from the focus group session relating to barriers to medical care are reported here.

Participants. A total of 10 adults (9 male and 1 female), aged 18–30 years, with ASD participated in the focus group. The participants were recruited through members of the Aspirations Ohio program; a social and vocational skills support group provided by the Nisonger Center, a University Center for Excellence in Developmental Disabilities located in Columbus, Ohio. Participants were invited to meet in a private room at a familiar location to the participants for the focus group session and were situated around a large table for collaborative discussion. At the beginning of the session, all participants signed consent forms allowing the session to be recorded for the purpose of research and analysis. None of these individuals had intellectual disability and all were their own guardians and able to communicate verbally.

Procedures. Pre-prepared, open-ended questions were used to facilitate discussion and were designed to prompt participants to consider and share with the group how their current health care clinic makes them feel, how they think it should make them feel, and to discuss any barriers before, during, or after the clinic visit. One question in particular focused on which step(s) of the clinic experience were the most problematic. The approach used to analyze and synthesize the information collected at the focus group followed a typical process used by design researchers (Kolko, 2010): individual statements were extracted from audio recordings, arranged and clustered by similarity into categories to identify patterns, summarized into higher-level insights, and then configured into visual representations for communication purposes. Two of these visual representations are included (see Figures 2 and 3). They are the result of synthesized insights derived from the statements made by the individuals when prompted to describe the most stressful parts of the clinic visit. In Figure 2, the x-axis represents steps in a typical office visit. Each of the steps is represented here to show the full clinic journey and where high stress areas were identified along that journey in their discussion. The heights (stress) associated with each step of the journey are relative and not tied to specific numbers. The line is meant to visually indicate where higher areas of stress peak at specific stages of the clinic visit in relation to other stages. The "loop" in Figure 3 was created after the focus group as a visual representation of the verbal discussion had by three of the participants when describing how social interaction creates a positive feedback loop of increasing anxiety and stress that were carried into the clinical setting. A summary of the findings of this focus group (along with ideas generated by the participants with autism, shown in Figure 2) is also described.
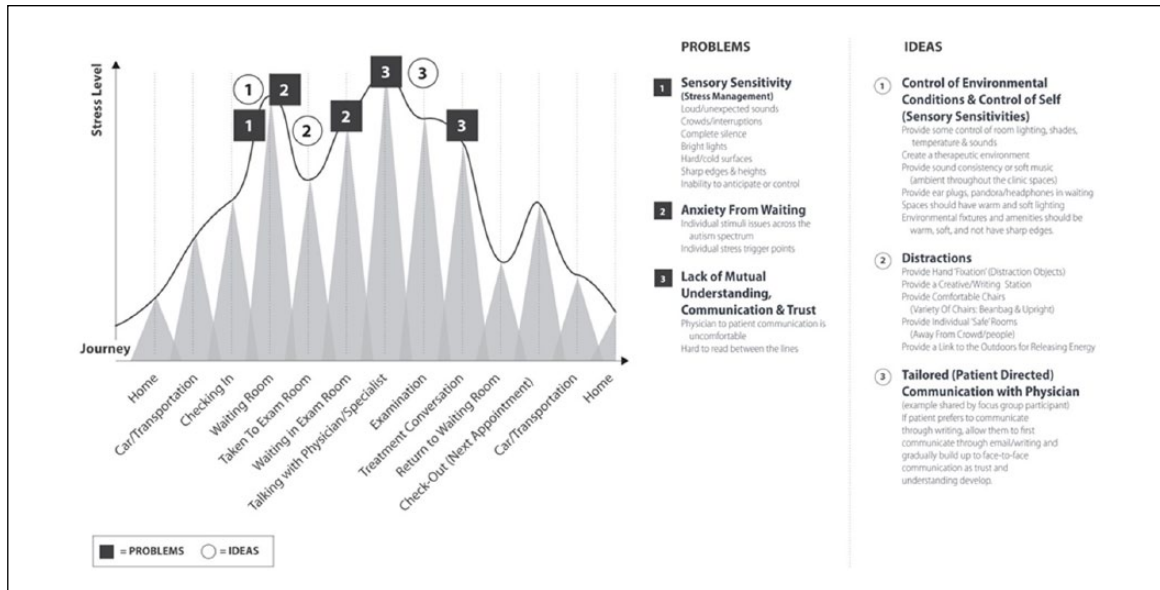
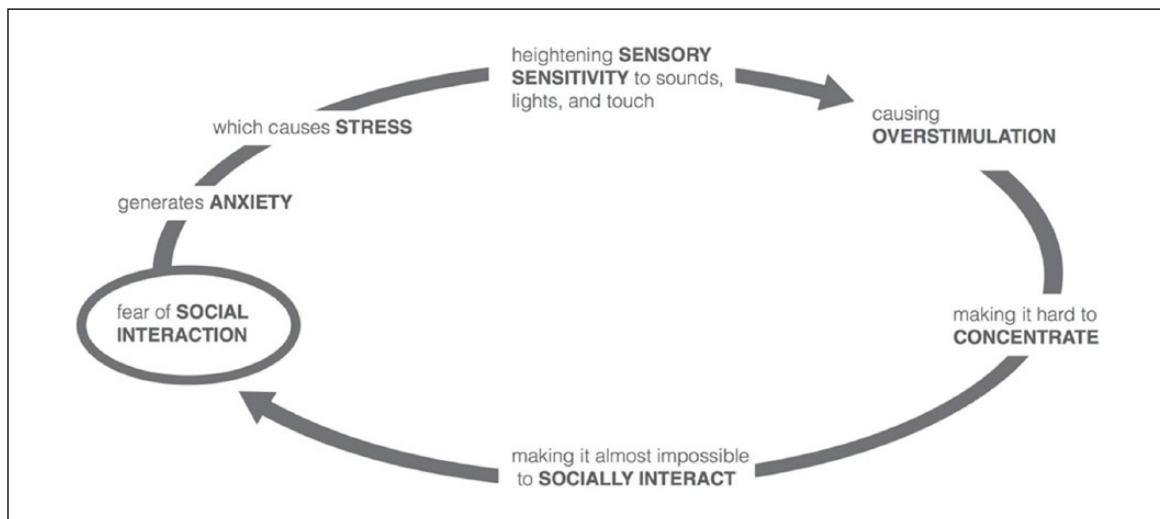**Figure 2.** Level of stress at different stages of a clinical visit (based on focus group findings).

Figure 3. Negative feedback loop resulting in difficulties in social interaction. Fear, prior to coming to clinic, is linked to the anticipation of social interaction which can cause some patients to spiral into heightened sensitivities which then make it hard for them to focus on a conversation and successfully interact with others.

Chart review results

During the study period, 146 patients called to schedule an appointment. Of these, 3 did not attend their initial appointment and 17 patients were under the age of 15 so their charts were excluded from data analysis. This resulted in a total of 126 charts reviewed. The ages ranged from 15 to 45 years old, with a mean age of 21.2 years. The majority of patients (n=116, 92%) were between the age of 15 and 29 years old, with 10 (8%) aged 30 or older. Patients were predominantly male, with 98 (78%) males and 28 (22%) females. Please refer to Table 1 for general demographic information regarding included patients. Frequency of medical diagnoses included the following: 49% (n=62) had intellectual disability, 49% (n=62) had ADHD, 52% (n=65) had anxiety, 41% (n=52) had obesity (BMI > 30), 31% (n=39) with a history of aggressive behavior, 31% (n=31) had depression, 22% (n=28) had seizures, and 9% (n=11) had hypertension.

Pre-visit assessment findings. From the total charts reviewed (n=126), 112 completed a pre-visit telephone assessment. Of these, only 74 charts were reviewed to evaluate for interventions completed based on pre-visit assessment

Table 1. Characteristics of the chart review study population, N = 126.

Characteristic	n (%) unless otherwise indicated
Demographics	
Sex	
Male	98 (77.8)
Female	28 (22.2)
Age, mean (SD)	21.2 (5.6)
15–19	60 (47.6)
20–29	56 (44.4)
30–39	6 (4.8)
40–45	4 (3.2)
Body mass index (BMI), mean (SD)	28.5 (7.2)
≤20, underweight (min = 17)	13 (10.3)
21–24.9, normal	24 (19.1)
25–29.9, overweight	27 (21.4)
≥30, obese (max = 58)	47 (37.3)
Unknown	15 (11.9)
Diagnoses	
Intellectual disability	62 (49.2)
ADHD	62 (49.2)
Anxiety	65 (51.6)
Obesity	52 (41.3)
History of aggressive behavior	39 (31.0)
Depression	39 (31.0)
Seizures	28 (22.2)
Hypertension	11 (8.7)
Medication use	
Antiepileptics	39 (31.0)
Antihypertensives	9 (7.1)
Atypical antipsychotics	48 (38.1)
Benzodiazepines	29 (23.0)
Nonstimulant ADHD	32 (25.4)
Other antidepressant	12 (9.5)
SSRI or SNRI	51 (40.5)
Sleep aids	32 (25.4)
Stimulants	27 (21.4)
Typical antipsychotics	11 (8.7)
Stool softeners	19 (15.1)
MRCI score	
Mean (SD)	14.7 (14.1)
Median (range)	10.75 (0–79.5)

SD: standard deviation; ADHD: attention-deficit hyperactivity disorder; SSRI: selective serotonin reuptake inhibitor; SNRI: serotonin–norepinephrine reuptake inhibitor; MRCI: Medical Regimen Complexity Index.

findings. The other 38 charts were not included due to missing information regarding whether individualized interventions were planned based on the pre-visit assessment findings. These data were unavailable for chart review because it was recorded in a location that was no longer visible 1 year after the initial visit date. For this subset of patients, the age ranged from 15 to 45 years with a

mean age of 20.8 years. There was no significant difference in medical diagnoses from the 74 charts compared to the total reviewed charts. In all, 23% (17 of 74) of patients had documented changes to the standard medical visit format. Comorbidities that were significantly associated with need for modification of the routine office visit included ID (40%, $p < 0.001$), seizures (45%, $p = 0.01$), and history of aggressive behavior (57%, $p < 0.001$). Of the 17 patients who had changes to the standard medical visit, 15 of 17 (88%) had at least one of these three comorbidities, with 6 patients having 2 of them and 8 patients having all 3. Specific needs and barriers included difficulty with the waiting room or waiting in general (n = 12) not liking noises including loud noises or children crying (n = 11), aversion to needles (n = 6), difficulty being touched (n = 6), history of aggression in a medical facility (n = 3), not liking bright lights (n = 2), and being unable to tolerate vital signs (n = 1).

Based on these concerns, our team created individualized plans to assist patients in successfully completing their initial medical appointment. Our most common interventions included rooming the patient immediately upon arrival and completing registration in the exam room (n = 16), not performing vital signs at the time of intake (n = 2), notifying the patient prior to touching them (n = 2), waiting in the car until the physician was ready to see the patient (n = 2), turning the lights out in the room prior to rooming (n = 1), scheduling them in the first appointment of the session (n = 1), and having a security guard present but outside the room and not visible to the patient (n = 1).

All 74 patients were successfully roomed and evaluated by the physician. Of those who underwent a pre-visit assessment and implemented personalized modifications, only seven patients had "adverse events" which consisted of being unable to get complete vital signs (n = 5) and being unable to complete portions of the physical exam (n = 2). Of the 14 patients who did not have a pre-visit assessment completed, one patient had an "adverse event" consisting of being unable to get complete vital signs.

Medication use. To characterize the use of medications in adolescent and adult patients with ASD, medication use for the 126 patient charts were reviewed. Medication use at the time of the initial visit included 51 (41%) on selective serotonin reuptake inhibitors (SSRIs)/serotonin–norepinephrine reuptake inhibitors (SNRIs), 48 (38%) on atypical (second generation) antipsychotics, 39 (31%) on antiepileptics, 32 (25.4%) on non-stimulant ADHD treatments, 32 (25%) on sleep aids, 27 (21%) on stimulants, 29 (23%) on benzodiazepines, 19 (15%) on stool softeners, 12 (10%) on non-SSRI/SNRI antidepressants, 11 (9%) on first-generation antipsychotics, and 9 (7.1%) on antihypertensives. Additionally, 39 patients (31%) reported current use of complementary and alternative medicines with an additional 13 patients (10%) reporting previous

Table 2. Association of medication use with select comorbidities in patients with ASD.[a]

Medication	Aggressive behavior (n = 39)	No aggressive behavior (n = 87)	p-value
Antiepileptics	22 (56.4)	17 (19.5)	<0.001
Antihypertensives	5 (12.8)	4 (4.6)	0.1
Atypical antipsychotics	26 (66.7)	22 (25.3)	<0.001
Benzodiazepines	16 (41)	13 (14.9)	<0.001
Nonstimulant ADHD	14 (35.9)	18 (20.7)	0.07
Other antidepressants	6 (15.4)	6 (6.9)	0.13
SSRI or SNRI	13 (33.3)	38 (43.7)	0.27
Sleep aids	18 (46.2)	14 (16.1)	<0.001
Stimulants	5 (12.8)	22 (25.3)	0.11
Typical antipsychotics	7 (17.9)	4 (4.6)	0.01
Stool softeners	12 (30.8)	7 (8)	<0.001

Medication	Seizure (n = 28)	No seizure (n = 98)	p-value
Antiepileptics	16 (57.1)	23 (23.5)	<0.001
Antihypertensives	5 (17.9)	4 (4.1)	0.01
Atypical antipsychotics	13 (46.4)	35 (35.7)	0.3
Benzodiazepines	11 (39.3)	18 (18.4)	0.02
Nonstimulant ADHD	8 (28.6)	24 (24.5)	0.66
Other antidepressants	2 (7.1)	10 (10.2)	0.63
SSRI or SNRI	15 (53.6)	36 (36.7)	0.11
Sleep aids	12 (42.9)	20 (20.4)	0.02
Stimulants	0 (0)	27 (27.6)	<0.001
Typical antipsychotics	3 (10.7)	8 (8.2)	0.67
Stool softeners	9 (32.1)	10 (10.2)	<0.001

Medication	Intellectual disability (n = 62)	No intellectual disability or unknown (n = 64)	p-value
Antiepileptics	27 (43.5)	12 (18.8)	<0.001
Antihypertensives	7 (11.3)	2 (3.1)	0.08
Atypical antipsychotics	31 (50)	17 (26.6)	0.01
Benzodiazepines	22 (35.5)	7 (10.9)	<0.001
Nonstimulant ADHD	17 (27.4)	15 (23.4)	0.61
Other antidepressants	7 (11.3)	5 (7.8)	0.51
SSRI or SNRI	25 (40.3)	26 (40.6)	0.97
Sleep aids	23 (37.1)	9 (14.1)	<0.001
Stimulants	7 (11.3)	20 (31.3)	0.01
Typical antipsychotics	9 (14.5)	2 (3.1)	0.02
Stool softeners	17 (27.4)	2 (3.1)	<0.001

ASD: autism spectrum disorder; ADHD: attention-deficit hyperactivity disorder; SSRI: selective serotonin reuptake inhibitor; SNRI: serotonin–norepinephrine reuptake inhibitor.
Number (%) taking each medication for those with and without each comorbidity.
[a]Analyses were not corrected for multiple comparisons.

use of complementary and alternative medicines. The average number of different medication classes taken was 3.1 for patients with ID and 1.8 for patients without ID. Further statistical analysis was performed to better understand the relationships of different comorbidities with specific medication class usage with a particular focus on ID, seizures, and history of aggressive behavior. These data are provided in Table 2. (Of note the analyses were not adjusted for multiple measures.) Comparisons for individuals with anxiety (n = 65) and without anxiety (n = 65) for SSRI/SNRI showed more frequent use in patients with an anxiety diagnosis, 35 (53.8%) versus no anxiety 16 (26.2%), p < 0.001. For the obese (n = 52) versus non-obese (n = 74) patients, use of atypical antipsychotics was not statistically significantly higher (21 vs 27, p = 0.66), respectively. Comparatively, typical antipsychotic use was higher for obese (9) versus non-obese (2), p ≤ 0.001). The average MRCI score for the total

Table 3. MRCI scores by diagnosis.

Diagnosis	MRCI, mean (SD)	MRCI, median (range)	p-value versus patients without the diagnosis
Intellectual disability (n = 62)	20.0 (16.7)	16 (0–79.5)	<0.001
ADHD (n = 62)	13.0 (11.7)	8.5 (0–59.5)	0.24
Anxiety (n = 65)	13.5 (10.6)	10.5 (0–40)	0.84
Obesity (n = 52)	14.8 (11.7)	12 (0–59.5)	0.41
History of aggressive behavior (n = 39)	25.8 (17.8)	23.5 (2–79.5)	<0.001
Depression (n = 39)	11.2 (8.5)	8.5 (0–36.5)	0.15
Seizures (n = 28)	21.7 (12.3)	20.5 (0–57)	<0.001
Hypertension (n = 11)	21.7 (16.5)	21 (2–57)	0.09

SD: standard deviation; ADHD: attention-deficit hyperactivity disorder; MRCI: Medical Regimen Complexity Index.

population was 14.7 (range, 0–79.5). MRCI scores were significantly higher for patients with ID (mean MRCI score of 20.4, $p < 0.001$ vs non-ID), patients with seizures (mean MRCI score of 21.7, $p < 0.001$), and patients with a history of aggressive behavior (mean MRCI score of 25.8, $p < 0.001$) (refer to Table 3).

Focus group results

When asked which stages of a clinic visit were most problematic, participants reported that communicating with the physician, the physical exam, and the waiting room experience were the most stressful portions of the evaluation (refer to Figure 2). Additionally, they described the anticipation of social interaction with the medical team as a negative feedback loop, a self-fulfilling prophecy which contributed a great deal to their increased stress (refer to Figure 3). Overcome by anxiety and overstimulation, this inhibits their ability to focus and communicate well with the medical staff. Overall, the group consensus was that sensory sensitivity, control (empowerment) within the space, and communication barriers needed to be addressed to achieve the best outcomes in a clinical setting.

Discussion

Although it is clear that adults with ASD experience health care disparities and challenges in health care settings, little is known about what contributes to those disparities and how to address these barriers. Our findings are among the first to describe the challenges and opportunities in adult medical care settings for these patients as they transition from pediatric to adult care settings. Our results highlight multiple possible contributors to health care needs as well as potential areas to focus on in overcoming these disparities.

Our population includes both pediatric and adult-age patients, with the majority of our patients in late-adolescence or early adulthood. There was a predominance of males consistent with previously reported prevalence rates (Christensen et al., 2016). Almost half of our patients had an ID based on patient or caregiver report. This is higher than the CDC's reported rate of ID (31.6%) in patients with autism. This difference could be due to the manner of determining the presence of ID, as we did not confirm the presence of ID with any formal testing. It is also possible that patients with ID were more likely to seek out our program instead of obtaining care from another primary care provider in the area.

Both the focus group and our pre-visit assessment identified the waiting room and waiting time as barriers to care. In all, 23% of our patients received modification to the standard patient flow in our primary care office. Patients with ID, history of aggressive behavior, or seizures were more likely to need adjustment to the standard patient flow. The most commonly utilized modification was to bypass the waiting room to avoid the stress or anxiety associated with that setting. By employing a telephone-based pre-visit assessment, we were able to provide medical care for all adolescent and adult patients with ASD by pre-planning individualized accommodations to overcoming these barriers. Based on our findings, those most likely to benefit from these accommodations are those with ID, history of aggressive behavior, or seizures. As 90% of patients needing individualized accommodations had at least one of these three conditions, these comorbidities may be useful in screening for patients that need additional support. Although the methods used in our office may not be possible in all medical offices, we believe that if medical providers institute similar pre-visit screening assessments, they can help patients overcome barriers to care and improve care for adults with ASD. Our work did not address barriers experienced by medical providers caring for adults with ASD. Further work will need to be done to better understand those barriers and how to overcome them.

The focus group identified communication with providers as a significant concern, as well as the lack of comfort and empowerment felt by people with ASD in the waiting environment. Resolutions offered by the participants included creating tailored communication channels between patients and providers, and creating a clinical

environment that was more calming (e.g. rounded corners and white noise) and gave them more control over managing their stress (e.g. the ability to self-soothe with wait-time distractions or retreat to a quiet room, or be given a count-down clock to know how long they will have to wait). Taking these needs and desires into consideration may help to improve communication and comfort, not only for the ASD individual but also for the providers and staff. Further work will need to be done to identify effective tools to aid communication in primary care settings.

Furthermore, outcomes from the focus group session support the value and contribution potential of people on the autism spectrum in more empowered roles to express the needs and desires of this population as they relate to the medical care experience. It also helps the medical community better understand their unique perspective and work with designers and providers to conceptualize new resolutions targeted at improving patient/provider interactions and the clinical experience.

We described the frequency of different medical comorbidities in our population of people with autism. Understanding this is important for physicians seeing patients with ASD so they can appropriately anticipate and screen for medical comorbidities. Although this is well described in pediatric patients, few studies have evaluated this in adults with ASD. Previous studies have shown adults with autism have higher rates of seizures, depression, anxiety, and obesity (Croen et al., 2015; Fortuna et al., 2016). Our findings showed comparable data with 22% of patients with seizures, 37% with obesity, 29% with depression, and 51% with anxiety. Our rates of depression were higher than those reported by other recent work (Fortuna et al., 2016). Further work will need to be done to better define the prevalence of these conditions in adults with ASD. Although our population was a primary care–based population, it is possible that those with fewer medical needs did not seek out our clinic, so our data may reflect a population with higher medical needs than the general population with ASD.

Finally, we evaluated medication use in patients with ASD. We found that many adults with ASD are on multiple medications, with the majority of these having psychotropic effects. A recent report (Jones et al., 2016) found that there was no significant difference in the frequency of medication use across intellectual abilities, with the exception of a higher benzodiazepine use in the ASD population that had severe ID. We also found a higher benzodiazepine use in patients with ID; however, we found a significantly higher rate of use of atypical antipsychotic, typical antipsychotic, antiepileptic, sleep aid, and stool softener use among the patients with ID compared to those without ID. Interestingly, in our data, the use of atypical antipsychotics did not correlate with obesity, although there was a trend toward significance.

Additionally, we found high rates of psychotropic medication use in patients with seizures, anxiety, and a history

of aggressive behavior. These data highlight the need for careful monitoring and awareness of the risks of polypharmacy in patients with ASD, particularly if they have ID, seizures, or challenging behaviors.

We report an average MRCI score of 14.7 in our population. Prior work in children with ASD had reported an average MRCI score of 83.6 (Logan et al., 2014). One of the limitations of the previous paper was the use of a Medicaid database to collect the medication use data. The previous authors' application of the MRCI was significantly different as the MRCI score was calculated as the sum of all medications prescribed during a 2-year period. Comparatively, in our study, the caregiver or patient provided the medication list and use instructions during the pre-visit assessment and/or initial clinic visit, so one specific regimen was used at one point in time to calculate the MRCI score. This is consistent with the implementation method used in the original MRCI tool development study (George et al., 2004). Based on this, a direct comparison between their 2-year cumulative MRCI score and our patient-specific MRCI regimen score cannot be made.

Prior work demonstrated that completion of the MRCI tool required 2–8 min depending on the regimen complexity, and inter-rater reliability was very high (George et al., 2004) which supports the application of the tool in our setting and for use by others.

Further validation of the MRCI tool was conducted in a population with increased number of comorbidities including diabetes, hypertension, and geriatric depression (Hirsch et al., 2014). Thus, the MRCI score has been suggested as a more robust risk assessment tool to identify patients on potentially problematic medication regimens that ultimately may impact patient adherence and outcomes (Hirsch et al., 2014).

Comparison to other MRCI scores (including both prescription and over-the-counter products) are as follows: hypertension (18.0; range, 2–50), diabetes (20.5; range, 4–72.5), and both hypertension and diabetes (27.0; range, 6–89) (Rettig et al., 2013). The mean number of medications for each group was 9.0, 8.0, and 12.0, respectively. Our overall MRCI score was 14.7 (range, 0–79.5) which may reflect our young population requiring fewer medication since the number of medications directly affects the MRCI results (George et al., 2004). We did find a higher MRCI score in those with ID (20.4), those with seizures (21.2) and those with history of aggressive behavior (23.7). These scores are consistent with a Medicare Part D population receiving specialized medication management services (mean MRCI, 21.5; range, 8–43) (Moczygemba et al., 2012). These data highlight the high complexity of medication regimens in patients with ASD. It is important to consider that patients with ASD may be least able to self-advocate, manage their own medications, and communicate with their physicians related to them. Thus, they are at a high risk of polypharmacy challenges. Providers should keep this in mind as they provide care for patients

with ASD and involve specialists, pharmacists, or other support as needed to ensure safety in medication prescribing.

Improving the complexity of medication regimens should be a part of the medical decision-making process. The initial step is the recognition of the potential risks involved for patients with ASD by utilizing the MRCI tool. Individualized plans to simplify the regimen could include actions directed at limiting the various dosage forms or simplifying the frequency of administration. It would be important to consider the contribution of each MRCI domain including dosage form, frequency, and additional directions to decrease complexity and adherence barriers.

Limitations

The majority of our data were collected by retrospective chart review. Although documentation of pre-visit assessments and clinical visits is standardized in our electronic medical records, there are inherent limitations to data collection in this format. Additionally, the focus group we report in this work was limited to a small sample size of participants, and only those individuals that could attend independently and communicate in a group setting, so it does not fully represent the breadth of adult patients with autism. This part of the research was exploratory in nature, intent on gaining an initial understanding of the underlying needs of patients with ASD (from their perspective) and identifying problem and opportunities within the clinic setting. The qualitative insights, derived from the focus group, are descriptive and without statistical analysis and will therefore need further study to confirm the findings. Despite these limitations, the data and insights drawn from both studies represent new information that furthers the understanding of the needs of patients with ASD.

Conclusion

By utilizing a phone-based pre-visit assessment, we were able to provide medical care for all adolescent and adult patients with ASD in a primary care office setting which accommodates all patients, not just those with ASD, by pre-planning individualized accommodations to overcome environmental and process barriers. Additionally, the focus group consists of adult patients with ASD identified communication with providers as a significant concern and suggested the possibility of tailoring communication between the provider and patient to the patient's needs, comfort, and abilities. Further work will need to be done to identify effective tools to aid communication in primary care settings. Finally, we found that many adults with ASD are on multiple medications, with the majority of these having psychotropic effects. The risk of complex medical regimens and potential adverse effects related to this complexity is heightened by the challenges in communication

between patients with ASD and their medical providers. Although additional work needs to be done in this area, our findings provide a better understanding of the current health care access and delivery needs of adolescents and adults with ASD.

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