

Identifying Clinical Staff Awareness and Accommodations for Adult Patients with Autism
Spectrum Disorders (ASD)

Submitted by
Sophia Simbeni

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Mentor: Mary O. Dereski, Ph.D.
Associate Professor
Department of Biomedical Sciences
Oakland University William Beaumont
School of Medicine

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Abstract

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder defined by challenges with social skills, communication, restricted interests, and repetitive behaviors. The Center for Disease Control and Prevention (CDC) estimates that there are 1:54 children with ASD. As these children reach adulthood, a paucity of resources and properly trained healthcare personnel to treat these individuals may exist. This project attempts to identify clinical staff ASD awareness and accommodation gaps in providing healthcare.

Methods

Data was collected from two populations. 1) clinical staff (e.g. nurses, medical assistants, receptionist) in primary care offices, and 2) adult patients with ASD and their parents or caregivers. Participants were recruited in collaboration with the Joanne and Ted Lindsay Foundation Autism Outreach Services Program (OUCARES). Recruitment efforts encompassed 30 offices, 4 events, and one listserv email to all OUCARES members. Survey responses were compared for common or unique themes.

Results

Participants included 3 clinical staff, 6 adults with ASD, and 1 parent. None of the clinical staff reported patient accommodations. Adults with ASD stated that the accommodations received were those they or their parents provided. Five of the 6 adult patients responded that they do not alert their physician offices about their ASD. Rather, parents disclose this information to the offices or no information is shared. Six out of 7 adult patients had parents accompany them to their appointments. Additionally, all 3 clinical staff members said that parents/caregivers should attend appointments.

Discussion

The low yield of participation may indicate an unwillingness to discuss ASD. The patient's reliance on parents to disclose or assist during appointments is reported, however this may not foster the patient-doctor understanding needed to provide optimal healthcare quality. The apparent disconnect between the primary care office staff, the adult with ASD, and specific accommodations that could facilitate care, should be further investigated.

Introduction

Autism Spectrum Disorder (ASD) is a common neurodevelopmental disorder that presents in childhood and is defined by challenges with social skills, communication, restricted interests, and repetitive behaviors (Fortuna et al, 2015). In 2019, the Centers for Disease Control and Prevention (CDC) estimated that about 1 in every 54 children has been identified as having ASD. The last 2 decades of children diagnosed with ASD are reaching adulthood, and even though it is a lifelong condition, healthcare resources and properly trained primary care physicians are rare for adults with ASD (Nicolaidis et al, 2016). Young patients with ASD generally have pediatricians who are well informed about the characteristics of individuals on the spectrum and are accustomed to their patient's specific behavior and any special accommodations required for healthcare delivery. However, when the patient reaches adulthood (turns eighteen years of age), they are expected to transition to a new adult primary care physician and little is known about the effect this transition has on interactions between patients, physicians, their clinical staff, and the quality of healthcare (Walsh et al, 2017). Even among groups of pediatric providers considered experts in caring for individuals with ASD, there is not much being done in terms of interventions and strategies for the transition from pediatric to adult health care for those with ASD (Kuhlthau et al., 2014). A recent study found that primary care physicians and nurse practitioners (NPs) were not confident in their ability to provide effective healthcare treatment to individuals with ASD, and did not feel prepared with the correct knowledge and resources to care for these patients (Iannuzzi et al., 2018).

In adult primary care physician offices, it has been found that collaboration between the primary care physicians and other members of the healthcare team encourages care/treatment coordination and can lead to better quality care (Matthys et al, 2017). Training of all health care

team members, including staff such as the office manager, medical assistants, social workers, nurses, and physician providers, is critical to ensure that patient-centered care for individuals is provided and delivered in an effective manner. Also, central to this care is promoting comfort and flexibility while meeting the special needs of the patients (Nathawad & Hanks, 2017).

Nurses, as key clinical staff members, are the largest percentage of the healthcare workforce, and function in all areas of healthcare (Queisser, 2016). Queisser et al. (2016) stated that nurses in primary care offices will encounter an adult patient(s) with ASD in their career, so nurses need the education and tools to be both knowledgeable about and confident in their ability to interact with individuals with ASD. It has been found that a lack of knowledge of ASD can lead nurses to have adverse feelings toward providing care and interacting with individuals with ASD (Giarelli et al, 2011). Giarelli et al (2011) also stated that better data collection and information for clinical encounters with patients with ASD across the lifespan and in all healthcare disciplines is required for more effective nursing workforce training in treating these patients. While some research has been done to evaluate primary care physician knowledge of ASD to aid with adults with ASD transition to adult primary care, there is a gap in research when it comes to all the other clinical staff and their knowledge and/or treatment accommodations for adult patients with ASD. Overall, clinical staff are an important, yet unexplored part of the healthcare team that need to be just as informed and prepared to interact with and deliver optimal healthcare to adult patients with ASD as the physicians themselves.

This project will attempt to identify gaps in the research concerning nurses and other clinical staff's awareness of the unique needs for patients with ASD and how providing potential accommodations may improve the healthcare delivery for this population. The approach was from both the clinical staff and from the patient's perspective. Clinical staff in primary care

offices that have treated adults with ASD were identified and were queried about accommodations implemented when treating young adult patients with ASD. Additionally, adult patients with ASD who have had experiences with clinical staff in primary care offices were asked to share their interactions.

Methods

The whole study was conducted over a period of no more than two years and two months. It was completed by February 2020, as outlined in the Honors College requirements for graduation. This project was conducted in two parts that were analyzed together to broaden the scope of the data collection. The first portion of the study looked at interviewing clinical staff (nurses, medical assistants, receptionist, etc.) in primary care offices that treat/have treated adult patients with Autism Spectrum Disorder (ASD), and the second part looked at interviewing adult patients with ASD themselves and their parents or caregivers.

Clinical Staff:

The first portion of the project was a study of clinical staff (nurses, receptionists, medical assistants, etc.) in primary care physician offices who have been identified as treating adults with Autism Spectrum Disorder (ASD).

Clinical staff working in the offices of primary care practitioners who treat patients on the ASD spectrum were identified. Participants were recruited by surveying individuals with ASD involved in the Oakland University Center for Autism Outreach Services (OUCARES). Information was gathered regarding their physician's offices. Additional recruitment was through a physician information survey distributed through the Autism Alliance of Michigan. Physician information collected was used to contact clinical staff at these offices. These organizations serve not only children with ASD, but many adults (> 18 years of age) as well. Previously obtained contacts through colleagues and other contacts were also used to increase the contact pool.

After identifying offices that currently or have in the past treated adults with ASD, primary care practitioners were requested to contact their clinical staff to be recruited for this study. Clinical staff members were then contacted by phone or email to ask if they would like to participate in this study. Finally, in-person visits to offices were made to recruit and paper copies of the interview in survey form were dropped off at offices to try to increase participation. This phase of recruitment happened over a period of 4 months with about 5-6 hours a week dedicated to researching, calling, and showing up in person to clinics to recruit. During this time, just over 30 offices were contacted over the phone multiple times, and about 15 offices were visited in person for recruitment purposes. All offices contacted were in Southeast Michigan, specifically within Oakland, Macomb, and Wayne counties.

At the end of this phase of recruiting, only 1 interview was scheduled. Therefore, amendments were made to the recruitment process and clinical staff were able to be contacted without the permission of the primary physician. Organizations such as the Michigan Nurses Association, and the Oakland University School of Nursing were also emailed for recruitment purposes. This phase of recruitment occurred for an additional 2 months before data collection ended.

With combined initial recruitment and amended procedures, recruitment in total only yielded 3 clinical staff participants; one primary care clinical staff, one oncology clinical staff, and one internal medicine clinical staff.

In total, recruitment of this portion of participants took place from May 2018 to August 2018, as well as additional recruitment in January and February 2019. (Figure 1)



Figure 1: The timeline of recruitment and interviews of clinical staff, including pauses in data collection from May 2018-February 2019.

Interviews of clinical staff were conducted in-person based on participant's availability, at their place of work. If a convenient time could not be identified, phone interviews were suggested or a paper copy of the questionnaire (shown in Appendix 1) in a self-addressed stamped envelope was dropped off at the office. Paper surveys were to be filled out by the participant and returned to the study researchers by mail. If participation was still not achieved from these office staff, then a link to a Qualtrics online survey was made available for completion.

Before participating in an interview, each member of the staff was provided an IRB approved information sheet, briefing them about the study which includes detailing their rights, anticipated benefits, possible harms, and the option to withdraw from the study. Each participant was also made aware that the interview would be held individually and would be digitally voice

recorded for analytical purposes. Participants were able to read an information sheet and ask any questions they had about the study prior to giving consent to participate in the study. They were also given a copy of the interview questions for reference (Figure 2 and Appendix 1).

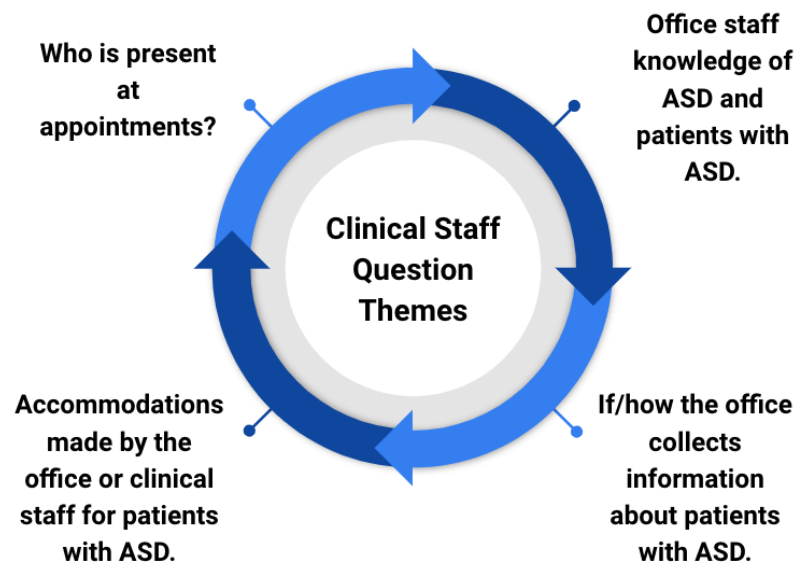


Figure 2: Key themes of the interview and survey questions for the clinical staff participants.

Interviews of clinical staff took place from June 2018 through February 2019 (9 months). At the end of data collection, two in-person interviews were conducted, and one online survey was completed. Both in-person interviews were conducted in the clinical staff's office. One was a small one-physician primary care office, the other was a large multi-physician practice internal medicine office. The completed online survey came from a nurse in an oncology unit and was thus a different office environment than the other 2 responses.

All data was compiled and stored on OakShare, which is a secure and encrypted server available to all faculty and staff at Oakland University.

Adults with ASD + Caregivers:

For this portion of the study, two different populations of participants were recruited. The first were adults with ASD (ages 18-35) who self-identified as having high functioning autism (verbal, willing and able to communicate by expressing their thoughts and ideas when responding to questions), with the second population being parents or caregivers of adults (18 year of age or older) with high-functioning autism. Participants were required to have the ability to sit through and participate in a 20-minute in-person interview, and also feel comfortable answering questions about their experience or lack-of experience in an adult primary care office.

Recruitment of these individuals took place from October 2018 through February 2019, and included the following methods:

1. A recruitment flier summarizing the purpose of this project, the guidelines for eligibility, and contact information of researchers was distributed at Oakland University's OUCARES events (4 in total) and emailed to OUCARES participants once (a mailing list of over 5,000 people).
2. In-person group announcements along with distribution of the recruitment fliers was made by the Principal Investigator (PI) before or after 3 OUCARES events. Participants self-identified as either an adult (age 18-35) with high functioning ASD, or as a parent/caregiver of an adult with ASD, and they notified the PI in person at the event or through email if they wanted to participate in an interview. Interviews took place at the time of recruitment if possible, or contact information (phone number and/or email address) was collected to determine a convenient time and location for the interview.

In-person interviews were arranged and conducted by the Principal Investigator on the Oakland University campus or a location of another OUCARES event during the time period of

January 2019 through March 2019. Five of the interviews were conducted at the time of recruitment at an OUCARES event. One adult and one caregiver interview were arranged for a future OUCARES event. There were a total of 7 interviews, 6 adults with ASD and 1 caregiver.

After recruitment and before participating in the interview, the participants were given a consent form to read through that explained the research study, ask any questions they may have and sign if they consented to participate. Participants could take a copy of the form with them in case they had any questions after the interview. Signed consent forms were stored in a locked cabinet in the Faculty Advisor's office.

For the sake of the ASD participants' ease and comfort, they were offered a copy of the interview questions (Figure 3 and Appendix 2) in advance of the actual interview to review for a few minutes and were encouraged to take breaks and ask questions for clarification during the interview if needed.

Interviews of individuals with ASD were conducted in settings, both time and location, that took into account specific ASD accommodations, such as sensitivity to sound or light, or other environmental stimuli.

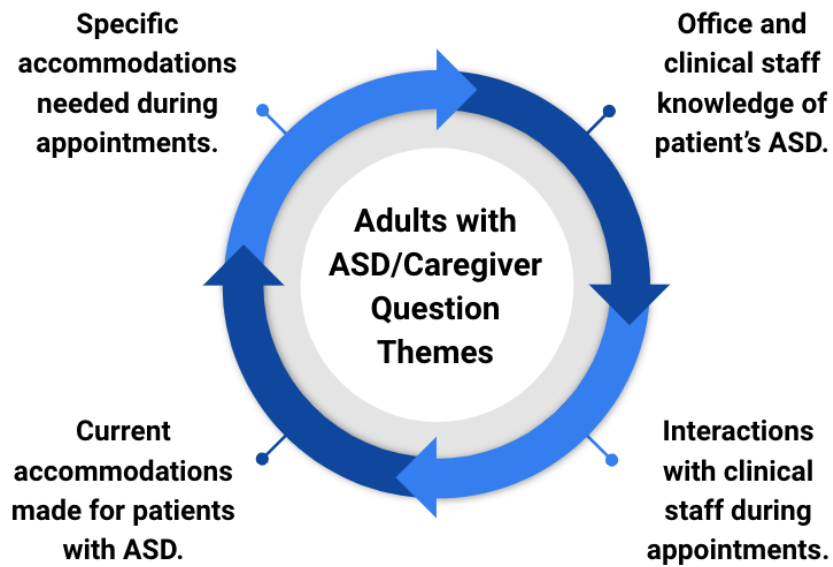


Figure 3: Key themes of the interview and survey questions for adults with ASD and parents/caregivers.

After the interview was complete, the participants were presented with a small item of appreciation. In-person interviews were recorded and transcribed, and all transcriptions were stored on Oakshare.

Results

At the end of data collection, 3 interviews with clinical staff (Group 1) and 7 interviews with adults with ASD and/or caregivers (Group 2) were obtained. Key themes were identified from the responses given by the two participant groups.

Group 1: Clinical Staff

Who is present at the appointments with the young adult with ASD?

2 participants stated that either a parent or caregiver is always at the clinical appointment with their young adult patient with ASD. All of the clinical staff stated that a parent or caregiver should attend all appointments with their adult with ASD regardless of adult status.

Office staff knowledge of ASD:

Only one participant obtained information about the patient from previous physicians through an electronic medical records system, although this information may not have been ASD specific. The other 2 participants had been seeing the adult patients since they were children, therefore they knew about the patient's ASD, the patient's preferences, and could identify any accommodations needing to occur during the clinical encounter. Two participants stated that they would be interested in a continuing education course to learn more about ASD and how to treat those patients.

Current office accommodations:

All 3 clinical staff participants stated that they were not instructed to provide any specific accommodations or given an office protocol for patients with ASD. Additionally, none of the

clinical staff participating had access to questionnaires available for the ASD patient in their offices. The majority (2 of the 3 staff participants) stated that in their offices, patients with ASD are treated like all other patients whenever possible. When clinical staff were queried about accommodations, 2 of the 3 participants stated that they made their own accommodations based on the individual patient to improve their experience at the office. These included being more patient and taking time with patients to explain terms and help them understand what is happening during their appointment.

Group 2: Adults with ASD and Caregivers

What type of physician is the young adult seeing and who is present at the appointment?

All participants see a physician regularly, but only 3 of the 6 adults with ASD and the 1 parent participant knew what type of physician they or their young adult were seeing. All of the participants that could identify the type of physician, stated that they were seeing a family medicine physician. Additionally, all of the participants, except for one adult, stated that a parent or caregiver is in attendance at all physician office visits.

Office staff knowledge of patient's ASD:

Only 1 patient disclosed themselves as having ASD. All other adult patients stated they didn't know if the office was explicitly told or their parents told the office about their ASD. The one parent participant stated that she used to inform doctors and clinical staff when their child was young, but has not done this since the patient became an adult. Only 1 adult patient said they knew for sure that clinical staff was currently aware of their ASD. The other 5 adults with ASD stated that they were unsure if the clinical staff knew or was ever told about their ASD. Two of

the adult participants stated that it would not matter to their treatment or office experience if clinical staff knew about their ASD.

Staff or patient accommodations:

All adults with ASD and parents/caregivers, stated that offices make no specific accommodations for ASD patients, but that there were specific accommodations that they would request or have implemented themselves (Figure 4). There are general forms filled out about health history during office visits, but no ASD specific forms or questionnaires were made available to any of the participants. Additionally, only 2 adult patients with ASD said they would fill out ASD-specific forms if available. The parent participant stated that if forms were an option, she would ask her adult with ASD if it was ok to fill them out.



Figure 4: Example accommodations suggested by adult participants with ASD.

The parent participant made a very interesting point about office knowledge and awareness of their patient's ASD, and whether accommodations should be made for these patients even if they do not disclose that they have ASD:

“I think that’s important to know...so even though people may be really willing to support and make accommodations, there are [young adults with ASD] who just don’t want that. And they might still need it. You can accommodate without them knowing. Maybe you are seeing adults with ASD and don’t know, maybe they are and [adults] don’t want to share, or maybe they’ll be willing to share with expectations that you will know what to do.”

Experiences with clinical staff:

When asked about their experience interacting during an appointment, 4 of the 6 adults with ASD said that they find it hard sometimes to communicate with staff, and the 1 parent participant stated that even if the adult doesn’t see it, there is a bit of a disconnect between the patient with ASD and the doctor and staff if they are not knowledgeable of ASD. Only 1 adult with ASD noted that they had a bad experience with a clinical staff member.

Discussion

The results found during these interviews provided valuable information about what adults with ASD, as well as clinical staff in primary care offices know about each other and what the expectations for a doctor's appointment may be as indicated by all participants.

Staff Knowledge and Comfort treating patients with ASD:

The very lack of clinical staff participation may be the most significant piece of data collected for this portion of the study. Initially, the offices contacted were identified by the patients themselves. After these offices were contacted, the clinical staff responded in one of two ways. They claimed not to know if they were treating any patients on the spectrum, or were non-responsive after repeated attempts to obtain an interview or complete a survey. This may indicate that clinical staff, even in offices where the primary care physician may know that they have patients with ASD, were unaware or unwilling to talk about these patients even under conditions of anonymity. Although the reasons for this lack of information sharing was not determined, it may be due to a lack of knowledge or the perceived inability to adequately discuss the topic. Future studies may be able to discern and overcome the reason(s) for this resistance to discussing treatment parameters for these patients.

Two of the clinical staff participants had been treating adults with ASD since they were children. This is indicative of the challenges that adult primary care offices are facing. Many children with ASD go to the same doctor or pediatrician's office for as long as possible. Continuity of healthcare may be important to many individuals with ASD or they are unable to identify a knowledgeable adult health care provider as they transition to adulthood.

However, eventually they will need to transition as they ‘age out’ of pediatric care or will feel as though they do not belong among the children being treated by that physician. As this milestone approaches, they will need to identify primary care physicians and staff who are aware of ASD in adults and have the ability to effectively administer healthcare to them.

The majority of adult patients participating in this study stated that they haven’t told physicians or office staff about their ASD themselves or they were unsure if office staff were aware. This begs the question of whether doctors and staff can recognize common signs of an individual with ASD without the patient or parent/caregiver disclosing the information. Only 2 adult participants were sure that clinical staff in the office knew they had ASD. This is also an area of concern since it indicates that although a physician may be aware, the staff might not be informed. Additionally, a few of the adult participants with ASD said that it would not make a difference to them or their clinical experience if the staff knew they were on the spectrum. This result is important if you consider a few variables. Autism is a spectrum, so each person who presents has different needs depending on their level of physical and cognitive ability. Therefore, some individuals who are high functioning may not feel the need or wish to disclose that they have ASD. This may occur because they would like to be viewed and treated no differently than their peers. Therefore, it may not make a difference in quality of care if the staff is aware that the patient is on the spectrum. However, if staff were trained to recognize the signs and make small accommodations for that patient’s care without having to be explicitly told, it could improve the quality of healthcare.

Because adult and parent participants stated they had not specifically filled out forms concerning their ASD and all of the staff stated there were no ASD specific questionnaires at their offices, the physician’s office would likely only be aware if the patient or their caregiver

disclosed the diagnosis. The addition of healthcare education about ASD for clinical staff may allow the provider to identify signals and signs that would improve healthcare quality if accommodations were implemented.

Parents/Caregivers Presence at Appointments:

The staff participants all agreed that it would be best if a parent or caregiver came to appointments with the adult, and the majority of adult participants stated they have a parent or caregiver go to appointments with them to help answer questions or explain ASD to the physician and/or staff. However, the question remains about what happens when the adult reaches a later age and the parents are no longer able to accompany their adult patient? There need to be more advocates for these patients than just their parents/caregivers. Physician's offices should be prepared for the appearance and subsequent treatment of these patients. Having a proxy/mediator available to the patient in a new patient situation may be advantageous. Conversely, having that individual at all appointments could prevent the physician/clinical staff and patient from connecting and building a relationship that could lead to better quality healthcare over the long term.

Accommodations:

The fact that so few of the adult patients knew what type of physician they were seeing could cause a barrier to care. It may cause uncertainty about what type of questions to ask or the treatment and follow up that would be needed.

Staff stated that they treated patients like other neurotypical patients, but patients with ASD may need extra care and might be uncertain of how to ask for it themselves. Clinical staff

should be able to recognize the signs of ASD and adjust care accordingly. A solution may be to supply more education about ASD to all levels of health care providers.

The most common answer from adult participants for accommodations that would be helpful was making an appointment that doesn't require a long wait time. This could be the first appointment of the day or the first after the staff lunch break. Another patient supplied suggestion was to take longer to explain terms or procedures while they are in the office. Patience and making sure that ASD patients know exactly what to expect during appointments, with staff and physicians, seems to be important for their comfort. It should be recognized that if the healthcare provider does not know how to treat the young adults on the spectrum, it may/will lead to frustration on the patient's part.

Many of the adults with ASD stated that they found it hard to communicate at various times with office staff. Participants stated they need do things such as:

- Better explain terms and procedures;
- Be more patient;
- Be more knowledgeable about ASD in cases where the patient doesn't disclose;
- Not expect eye contact; and
- Allow for more consistency in staff.

Although some of these accommodations, like staff consistency, are not feasible in all office settings, alternatively physicians and staff can take extra time to explain in depth what is going to happen during the appointment or answer questions. Small changes can make a huge difference.

Overall, the lack of participants, current protocol, and specific accommodations for adult patients with ASD, lead to more questions than answers about the interaction and relationship between adults with ASD and the clinical staff in those office settings. Perhaps all staff could benefit from education and training about recognizing the signs of ASD and possible accommodations for those patients resulting in a higher quality healthcare.

Limitations/Changes:

This study had several limitations. The sample size was extremely small in both populations interviewed. This led to observations and conclusions being drawn that are short-reaching. The limited participant clinical staff pool (n=3), is reflective of the difficulty of engaging clinical staff and obtaining information about their interactions with adults with ASD. Over 100 hours alone, and probably over 200 combined hours were spent recruiting possible participants, making calls and sending emails, physically showing up to offices and events, and conducting interviews. The lack of participants could be due to the area in which we recruited, the lack of participant time available, the manner in which we recruited, the lack of knowledge about adults with ASD in primary care, or a lack of knowledge about clinical staff role in a good office experience. Additionally, the study was limited to southeast MI, but reaching out to a broader participant pool may shift the study results. Possible changes to the study procedures would be using a solely online survey method and distributing to a farther reaching population. Additionally, collecting age of adults with ASD can help to compare younger to older adults, especially in terms of caregiver involvement and level of independence.

Future Applications:

Further applications of this thesis project would be to continue researching clinical staff roles with regard to patients with ASD interaction. Comparisons could be made based on patient load and office environment. Additionally, a possible continuing education course for nurses and other clinical staff may be beneficial in overall knowledge of ASD and possible accommodations that may improve healthcare quality for those with ASD.

Acknowledgments

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Appendix

Appendix 1: Clinical Staff Questions

Clinical Staff Survey Questions**Preliminary Questions:**

What is the medical specialty of the healthcare office you work in?

Interview Questions:

1. Does your practice have a protocol for caring for a patient with ASD?

If yes, please describe your protocol?

2. Does your practice utilize a patient toolkit or questionnaire for patients with ASD?

If yes, please describe what you use:

3. Do you obtain any information about the patient from their previous physician?

If yes, what information have you received and how do you utilize this information?

4. Do your patients with ASD bring a medical Proxy, friend or family member with them to an appointment?

- a. If yes, please describe who comes with the patient and what is their role:
- b. If no, would you suggest that a medical proxy, friend or family member comes with them (why or why not)?

5. When you become aware that a patient has ASD, what do you do with this information?

a. Is it documented in the patient's chart? YES/NO
If yes, how is it documented?

b. Is this information shared with the clinical staff? YES/NO
If yes, how is it shared?

c. If the answer to both A and B is no, please indicate if and how this information is used:

6. Are you instructed by the primary healthcare provider(s) to make accommodations for the patient with ASD?

If yes,
A. What are you asked to do?

B. If accommodations have been implemented, have you found that they provide a better healthcare delivery experience for the patient? Please describe:

7. How many patients visiting your office do you currently suspect have ASD?

- a. none
- b. 1-5
- c. 6-10
- d. more than 10

8. How many patients visiting your office do you currently know have ASD?

- a. none
- b. 1-5
- c. 6-10
- d. more than 10
- e. unsure

9. How old is your average patient you know has ASD?

- a. 18-25
- b. 26-30
- c. 30-35
- d. over 35
- e. unsure

10. Is there anything else you would like to share regarding providing medical care to your adult patients with ASD?

11. Would you be interested in taking a CME module focused on working in a healthcare setting with adult patients with ASD?

- A. Yes,
- B. No, Thank you.
- C. Unsure at this time

Thank you for your participation in this very important study. Your responses may help guide the healthcare for a large portion of the adult population with ASD.

Appendix 2: Adults/Caregiver Questions

Young Adult with ASD Interview Questions:

1. Have you seen an adult care Doctor for your routine office visits?
 - a. If no, why not and do you regularly go to a pediatrician?
 - b. If yes, do you know what type of Doctor it is? (e.g. Family Medicine, Internal Medicine?)
2. Does your doctor or the staff know that you have ASD?
 - a. If no, why not?
 - b. If yes, how did they find out?
3. Do you currently bring a family member/caregiver with you to your appointments?
 - a. If no, did you ever bring someone with you?
 - b. If yes, who do you bring and do they always go with you?
4. Have you ever had to fill out a questionnaire about yourself/ your ASD/your treatment preferences at a doctor's office?
 - a. If no, would you fill one out if it was available?
 - b. If yes, what did the form say/ask?
5. Does your Doctor's office do anything that makes your office visit go easier?
 - a. If no, what would you like them to do differently?
 - b. If yes, what does the Doctor or staff do to make your visit go easier?
6. Does the medical staff (nurses, medical assistant, laboratory staff) know you have autism?
 - a. If no, would you want them to know? Why or why not?
 - b. If yes, do you think it helps with your office visit?
7. Do you find it hard to communicate with the nurses and other office staff?
 - a. If no, what should they do to make it easier to communicate?
 - b. If yes, do you have any suggestions to make it easier to communicate?
8. Have you had any difficult experiences with clinical staff such as nurses or medical staff in a doctor's office? If yes, would you please tell me about it?
9. Do you think going through an online module that has information on what to expect at a Doctor's appointment would be helpful?
 - a. If the participant responds yes, please give them the online flier with the module information.
10. Please share anything else you think would be important for the staff at a clinical office to know about treating you.