ABSTRACT
Children with an autism spectrum disorder (ASD) have a higher annual mean number of total clinic, pediatric, and psychiatric outpatient visits, and inpatient and outpatient hospitalizations when compared to children without ASD. Families of individuals with ASD observe and experience specific barriers to medical care. Using a mixed-methods approach and interpretive phenomenological analysis (IPA), the perspectives of 40 families were gathered through a survey to gain a better understanding of positive and negative experiences, and the implications for healthcare providers and medical settings. Among the themes identified, families shared the need for healthcare providers to be more knowledgeable and trained about the heterogeneity of ASD, to presume competence and to view families as allies in facilitating medical encounters. As a result of these improvements, families also hope that healthcare providers develop greater compassion for families of children with ASD.

INTRODUCTION
According to the Centers for Disease Control and Prevention (CDC) and Autism and Developmental Disabilities Monitoring (ADDMD) Network (2018) reports that 1 in 59 individuals are diagnosed with an Autism Spectrum Disorder (ASD) in the United States. As the fastest growing developmental condition, striving to provide patient- and family-centered medical care is becoming increasingly necessary and difficult. Comorbidity is prevalent among this population, and it is estimated that more than 70% have concurrent conditions [1]. These medical concerns include neurological (e.g. Epilepsy), gastrointestinal disturbances, including nausea, vomiting, diarrhea, abdominal pain, and constipation, and respiratory and sleep issues [2,3]. Such coexisting medical concerns may necessitate a greater number of healthcare provider interactions across the lifespan for continuing medical management [4,5]. According to Croen and Gurney children with ASD had a higher annual mean number of total clinic, pediatric, and psychiatric outpatient visits, and inpatient and outpatient hospitalizations when compared to children without ASD [6]. Additionally, research shows that individuals with ASD utilize the emergency department (ED) at a higher rate, with studies reporting that adolescents with ASD access ED services up to four times as often as adolescents without ASD [2,3,7,8].

Additional barriers to providing medical care for individuals with ASD include inherently inflexible and harsh medical environments that may impact the sensory defensiveness of individuals with ASD. Volume, lights, odors, as well as prolonged wait times and the number of healthcare professionals prevalent in medical settings, may exacerbate features of ASD. Furthermore, limited training and resources to facilitate expressive and receptive communication, as well as address other sensory needs and behaviors may further complicate medical interactions. With the need for repeated physical examinations and invasive medical procedures in acute care settings, patients with ASD and their families may experience stress and anxiety [9,10]. Behaviors, such as noncompliance, aggressions towards property, others, and self as a result of the aforementioned barriers can interfere with assessment and treatment, and result in the use of restraints and seclusion [11].

The complexity of ASD in conjunction with coexisting medical conditions necessitates individualized patient- and family-centered care, which must incorporate the specific needs and strengths of the child. Though imperative in any medical encounter, this collaboration between healthcare providers and families becomes even more critical when a patient is one with ASD. Understanding how the disability manifests in each patient with ASD requires reliance on families. Families involvement in the medical encounter may help healthcare providers understand the triggers of
the child, apply preventative measures and de-escalation strategies, as well as help interpret and understand possibly idiosyncratic communications and behaviors of that individual with ASD [12-14]. This collaborative effort and involvement of families of individuals with ASD may lead to more effective medical practices and a more positive medical visit [9,10].

SIGNIFICANCE OF THE STUDY
While there are a number of publications on the perspectives of healthcare providers regarding the obstacles to providing medical care for patients with ASD, there is limited literature documenting the experiences, perspectives, and recommendations families of individuals with ASD during medical care interactions [15,16]. With the understanding that individuals with ASD are highly heterogeneous, it is notably important to deeply explore the unique perspectives of families. Collecting such comprehensive information will aid in the determining of clinical priorities and recommendations to guide medical delivery for patients with ASD, which provides effective strategies and resources, and increase healthcare provider awareness and knowledge. With a particular lens toward acute care settings, such as emergency departments, gathering family perspectives may provide a unique window in opportunities as well as potential barriers to effective care that may be specific to the acute care context. Through the experiences of families, proposed solutions may be explored to address the deficiencies in medical care for this high-risk population and their caregivers.

PURPOSE AND AIMS OF THE STUDY
Understanding the lived experiences of families of individual with ASD are essential in providing and improving upon comprehensive medical care for this population. Empathizing with families and the challenges they have encountered in medical settings will advance the individualized medical care of patients with ASD throughout their lifespan. The purpose of this mixed methods study is to gain a better understanding of the perspectives of these families. The specific aims of this study included the following:

1. Characterize the perspectives, concerns, resources, and barriers to ethical medical care of families of children with ASD.
2. Determine the recommended strategies and resources that could facilitate medical encounters, with a particular emphasis on the emergency department.

METHODS
Design
The study utilized a mixed method design to investigate the medical experiences and recommendations of families of individuals with ASD. Descriptive statistics were utilized to summarize closed-ended or Likert scale responses on the family surveys. The Interpretive Phenomenological Analysis (IPA) process was applied to explore the meanings and experiences families shared in written responses [17]. IPA was developed from Heidegger's philosophy that the concept and meaning of being cannot be disconnected from the person's world because the person's world shapes who they are: IPA aims to accurately present the voice of participants, seek a deeper understanding of the phenomena presented, and identify the commonalities and differences [18,19].

Within the purposes of this study, the approach also allows for researchers to discover, understand, and present the experiences of families voiced in the context of their world. By situating the study to the unique context of families of individuals with ASD, the experiences of families during medical encounters can be more accurately uncovered. These deep insights on how families experience and perceive medical encounters can inform and improve upon clinical practice across all medical settings. Furthermore, Pietkiewicz and Smith emphasize the practice of double hermeneutics, which involves the pairing of participant accounts of the phenomenon and the experiential themes, with the interpretations made by the researchers [17]. These interpretations may further support efforts to evolve the practices of healthcare providers and ensure responsiveness to the unique needs of individuals with ASD and families.

PROCEDURE
Institutional review board approval was received prior to recruitment. A parent survey was developed utilizing Campus Labs Baseline, a data-driven platform used to collect assessment data, to gather the perspectives of families on the medical care for their child with ASD. Families completed a digital consent form prior to accessing the survey questions. The survey included 7 questions, with 4 open-ended response opportunities for families to share their level of satisfaction with healthcare providers, the need for healthcare providers to have more training on working with patients with ASD, information that families wished healthcare providers knew when meeting and interacting with their child, and their experiences in emergency departments. The remaining 3 questions asked families to select responses to questions related to seeking out healthcare providers with experience working with individuals with ASD, hospitals with specific resources for the population, and their rating of their level of satisfaction with health care providers in terms of the care of their child with ASD.

The study took place in a state on the East Coast of the United States. Participants of this study were recruited through parent resource and advocacy groups for families with a child with ASD, as well as school settings. A recruitment letter for this study, which included a link to the survey, was distributed through e-mails, listserves, communication alerts, and social media. The study enrolled 40 families who had a child with ASD. Families were not compensated for their participation in the study.

ANALYTIC APPROACH
Qualitative analysis of open-ended survey responses was supported by NVivo 12, a computer-based data management and analysis software package. Analyses of written responses comprised of sequential layers of coding, categorizing, conceptualizing and theorizing, achieved by the following methods: open coding, axial coding, and selective coding [20]. Written responses provided by families were first extensively read, several times each, to ensure data immersion. Significant information and impactful quotes were highlighted and annotated as they were compared and contrasted to each other. Returning to and from the survey responses being reviewed and the annotations led to the emergence of anchoring themes and subthemes. These identified initial themes and subthemes were organized and negative case analysis was conducted to explicitly search the qualitative data for exceptions to the emerging themes and subthemes. This process was repeated for each survey response collected to ensure a full range of relevant
and salient themes and subthemes for inclusion [21]. Recurrence of emergent themes and subthemes in families’ shared responses asserted validity of findings [22].

Prior to engaging in interpretive sessions, the research team was provided with all raw survey responses. During the interpretive sessions, the data and researcher-identified themes and subthemes were reviewed and discussed, which verified the results of the thematic analysis and refined the subthemes. Final themes and subthemes were compared for accuracy, defined, and connections between themes were made according to conceptual similarities to create organized clusters. Short extracts of the responses that were considered illustrative of the themes were also identified and confirmed. A final analysis was written adhering to IPA methodology as described by Smith and Pietkiewicz [17,23].

VALIDITY AND TRUSTWORTHINESS OF THE DATA

Key principles of qualitative rigor and methodological diligence were established through the upholding of trustworthiness, which consists of credibility, transferability, dependability, conformability, authenticity, and fit [20]. These criteria were met in the analysis of the data in this study. Credibility refers to the confidence of findings based on checks for accuracy in the interpretation of the data, and conformability refers to the confirmation of findings through sufficient demonstration of text quotes. Both were established through member checks during the aforementioned interpretive sessions. To reduce bias, the forestructure of the researcher was clearly stated up front. It should also be noted; however, that fore structure is considered an important aspect and strength of interpretive phenomenological work as it enhances the richness and deepness of the analysis [24,25]. Transferability provides clarity of the context in which findings were achieved and the relevance of study findings for understanding the phenomenon in question were upheld.

RESULTS

When asked whether families would be more likely to seek out a specific healthcare provider (i.e., doctor, nurse) for their child if they had experience caring for patients with ASD, 97.5% of families responded that they would seek out such a healthcare provider. Only one family did not respond to this question. When asked if families would be more likely to go to a hospital with specific resources for patients with ASD, 95% responded that they would go to such a hospital. One family did not respond, and another stated that they would not seek out such a hospital.

Table 1 indicates the responses to a question about the level of satisfaction with healthcare providers in terms of the care of their child with ASD.

The written responses from families of individuals with ASD centered around four main themes. First, families shared positive experiences and the characteristics embodied by those healthcare providers. However, within this theme families shared their fortune in identifying a healthcare provider willing to or experienced in providing care for patients with ASD. Some families expressed that seeking out and returning to these preferred healthcare providers resulted in additional costs. Families also recognized the variability in the quality of providers, and concern about other medical specialties, such as the emergency department. Second, families shared negative medical encounters and the lack of knowledge, training, and resources to support individuals with ASD based on sensory processing, behaviors, motor stereotypies, and comorbid medical conditions. Families also shared frustrations related to assumptions made by healthcare providers, perceived frustrations with patients with ASD, as well as the contextual challenges of the medical setting. Third, families identified the oftentimes lasting impact of these negative medical experiences on their child with ASD. These traumas included increased anxiety and fear. Lastly, families provided recommendations that were in response to these negative experiences and aimed to increase patient- and family-centered medical care. These recommendations focused on how best to interact with and include the patient with ASD and families during medical visits, address needs of the population, including sensory processing and behavioral needs, and the environmental constraints of medical settings.

Theme 1

Positive experiences in medical settings: Families shared that healthcare providers were compassionate and respectful during medical encounters with patients with ASD. Several subthemes were identified, which include families purposefully identifying healthcare providers with knowledge, training, and expertise in caring for individuals with ASD. Families believed that they were fortunate in finding or encountering these healthcare providers, or fortunate in being able to pay out-of-pocket for providers outside of their insurance network. However, despite these positive experiences with healthcare providers that embodied respect and patience, there was a concern about the variability of providers. Families expressed concern about medical care across the lifespan and across different specialties, such as emergency medicine.

Seek out and fortunate enough: Many families of individuals with ASD shared that they actively sought out healthcare professionals specialized in working with individuals with ASD. Some families had healthcare providers from the state ASD research institution and affiliated medical institution. Other families communicated in advance with doctors, nurses, and other medical staff about the

<table>
<thead>
<tr>
<th>Response</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very dissatisfied</td>
<td>4</td>
<td>0.1</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>14</td>
<td>0.35</td>
</tr>
<tr>
<td>Neither satisfied or dissatisfied</td>
<td>3</td>
<td>0.075</td>
</tr>
<tr>
<td>Satisfied</td>
<td>15</td>
<td>0.375</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>3</td>
<td>0.075</td>
</tr>
</tbody>
</table>

Note: One family did not respond to the survey question
specific needs of their child with ASD. Families expressed that they were fortunate or lucky enough to find healthcare providers or developed a rapport with healthcare providers that were understanding and willing to treat a patient with ASD. One family shared:

I’ve chosen health care providers that meet my children’s needs; however, most of my specialists don’t participate in/are out-of-network with my insurance. I am very satisfied with the care that they provide but I realize how fortunate I am to be able to pay out-of-pocket when necessary; if we couldn’t, I’m not sure I’d have the same satisfaction with my children’s care. It seems that the best providers choose not to participate with insurance, which is understandable, but sad for the families that could benefit.

This quote represents the potential inequitable access to knowledgeable healthcare providers for individuals with ASD. Families who are fortunate enough or are financially able to have high quality healthcare or the ability to pay additional fees for out-of-network providers, may have better access to medical professions with the appropriate training and expertise to care for patients with ASD.

Characteristics of healthcare providers: In describing healthcare providers, families shared that they experienced medical professionals who were compassionate, welcoming, respectful and patient, while also being thorough in providing care. As noted, families felt fortunate to encounter healthcare providers who embodied these characteristics, while others sought out healthcare providers who were trained and knowledgeable about the needs of the population.

Tenuous access to medical professionals with experience with patients with ASD: One family shared, “Just because I met a handful of health care workers that were understanding doesn’t mean they all are.” Other families shared that they were satisfied with the care pediatricians provided, but were specifically concerned about the care provided in emergency rooms. Additionally, one family shared that though pediatricians were compassionate, there was concern that as their child grew older that healthcare providers in adult medicine would not provide the same patient-centered care and be responsive to the needs of their child with ASD.

Theme 2 Negative experiences in medical settings: The oftentimes the inflexibility of medical environments are not responsive to the needs of patients with ASD. Bright lights and noises may lead to increased anxiety and maladaptive behaviors. With limited knowledge and training, healthcare providers may respond to such behaviors with sedation and restraints, and not provide much needed empathy to address characteristics of ASD. Furthermore, families shared that this limited knowledge of ASD led to harmful assumptions, emphasizing the importance of increasing knowledge and training on how to best interact with patients with ASD.

Sensory processing: Medical environments may be uncomfortable for patients with ASD. One family stated, “Many seem oblivious to the potential sensory impact of their actions and procedures. Their offices are also not sensory-friendly.” Families shared that the bright lights in rooms and for medical procedures, and loud noises emitted from machines and monitors were a discomfort to their children with ASD. Another family shared that hospital gowns, due to their texture and fit aggregated the sensory issues of their child.

Understanding ASD and supports to address behaviors: A family shared, “Our child is not bad, she can’t control when [she is] overwhelmed and anxiety is at play.” Families stated that limited understanding of ASD by healthcare providers led to a lack of empathy when their child’s anxiety presented itself through defiance and behavioral outbursts. Another family shared: Wasn’t pleasant- My son was having an outburst, raging episode. Instead of hearing me and accepting the proof I had that he has autism. The doctor instead called security and a social worker in fear of his safety. Then they called a child psychiatrist who also didn’t want to accept his diagnoses. She tried to say he had mood disorder. Gave him some medicine that made him look like a zombie. Finally, after 2 days in the ER they finally agreed to his diagnoses of autism.

This family shared the frustrations of having healthcare professionals not take seriously the diagnosis and the knowledge of the family to support the patient. In this situation and in others shared by families, response to behaviors were aggressive and potentially traumatizing. As shared above, security was called. In another instance, a family shared, “Although they gave him a sedative, it either didn’t completely work or was wearing off. He had to be restrained by both parents and a nurse, and the doctor had bright lights shining on his face to do the stitches.” Similarly, another family shared:

He bit very deep into his tongue and I drove him to [an] ER horrible they had no idea what to do he flipped out full meltdown I had to call family members in to help hold him down for 4 hours since they would not give him a sedative because they could not do anything and he had to be transported to another ER once there they left me by myself with him in full meltdown aggressive neither ER did what they should have.

The reactive responses of medical professionals, as families shared, oftentimes included hospital security, as well sedation and restraints. Such responses were traumatizing for both patients with ASD and their families.

Complex medical needs including psychiatric needs: Common comorbidities for this population include sleep issues, dietary sensitivity, and gastrointestinal disturbances. Many families reported frustrations with healthcare providers not understanding these coexisting medical concerns. Other concerns expressed by families included the addressing of psychiatric needs and access to psychiatric beds.

In one case my child was physically violent and required to stay on the “adult side” of the emergency department because there was security. We were there for 12 days waiting for a bed to open at [a mental health treatment center]. Being on the adult side exposed my child and me to naked adults running through the halls, drug overdoses, explicit language and an overall unhealthy environment for a child.

Similarly, a family shared their experience with their child in a secure psychiatric ward of the emergency room, where they overheard interviews with users of drugs, survivors of suicide, and other mental health crises. Other families shared having to wait in the emergency room for a bed to be made available on a neuropsychiatric floor and the traumatic experiences from being exposed to aggressions from their child with ASD, with limited access to support, resources, and medication to address such behaviors.

Assumptions and training of healthcare providers: Families shared that with limited knowledge and training, healthcare providers made false assumptions and did not fully understand ASD. One
family shared that healthcare providers would not change their approach or interactions and provided care as if their child were neurotypical. One family shared, “They treat my daughter like every other child and she is not like every other child. They came in and grabbed her and didn’t try to explain anything to her. She was scared and had no idea what was going on.”

Other families shared that healthcare providers had limited experience with the disability and did not truly understand the heterogeneity. One family shared “I have had to educate physicians who practice adult medicine about ASD. One expressed surprised that someone with an autistic disorder (DSM IV) diagnosis could speak at all and wondered if this was a case of savantism or high IQ. (It is not).” Another family shared, “Because my son is verbal, many of the doctors and nurses who care for him speak to him as if he has the capacity to understand what they are saying. While he can speak he doesn’t have the capacity to always understand medical questions. He also particularly when not feeling well, he does not have the ability to quickly process their question and give a quick verbal response.”

Perceptions of healthcare providers: With limited training and understanding of ASD, families experienced little empathy from healthcare providers. One family shared, “We honestly try to avoid seeking medical care for our son unless absolutely necessary because providers tend to be very callous to our son and show zero empathy for a toddler having a sensory meltdown.” During medical encounters, families noticed looks of judgement and annoyance in response to behaviors and motor stereotypes.

Transitions and environmental constraints: Families shared that the protocols in medical environments can be difficult for individuals with ASD and their families. Transitioning to different locations can be especially challenging. Furthermore, multiple healthcare providers entering and exiting rooms, as well as collecting medical histories and other information repeatedly can lead to stress. Extended wait times, with no access to a quiet or sensory room, and limited resources to facilitate waiting and distract patients, can also be challenging.

Theme 3

As a result of these negative experiences, families shared that their children with ASD experienced anxiety and lasting trauma and fear of medical encounters.

Anxiety, fear and trauma: One family shared that being restrained in order receive stitches in the emergency room led to prolonged fear and anxiety for their child. One family shared a traumatizing experience that had sustained impact both on the family and child: My son fell and got a pretty deep cut next to his nose. He was very afraid and we had to papoose him and hold him down. The lower ranked nurse was very nice and patient. The nurse in charge and the one who had to suture him was not. She did not give him enough lidocaine, did not even wait for it to kick in. I could tell the other nurse was also shocked. My son was having a hard time staying still and she just wanted to get it over with as he was being loud and unruly. I kept asking if he could just be given a light sedative and let the lidocaine sink in and she said no just hold him still. He now has a horrible scar from those badly placed sutures and bad memories of that experience (he was 4).

Another family shared a similar experience of their child being restrained for stitches that led to fear and behavioral outbursts for following medical visits. Medical instruments and not understanding what was occurring also led to a great deal of anxiety and fear for individuals with ASD. As noted above, lack of psychiatric supports is also connected to families’ traumatic experiences.

Theme 4

Recommendations for healthcare providers and medical environments: These families, who have unique experiences with medical encounters, imparted recommendations on how healthcare providers and medical environments may be more responsive to the needs of patients with ASD. Families shared that by acting upon such recommendations stress and discomfort would be reduced, and would help both families and individuals with ASD become more trusting of healthcare providers.

Interacting with families and patients with ASD by adapting to the child before you: “Treat him like he’s a human being. Understand that he is terrified of you and he - and we - are doing the best we can”. Many families implored healthcare providers to empathize and understand families and patients with ASD by interacting with them. One family stated, “He hears you! He understands you! Insurance gives you 10 mins with a patient, but my son needs time to process”. Families no longer wanted healthcare providers to talk over their child as if the patient was not in the room or would not understand based on assumptions about ASD. Families wanted healthcare providers to take time to listen and understand patients with autism, and not make assumptions about the ability of a patient based on their limited verbal communication skills. Families recommended that medical professionals use visuals and assistive technology to facilitate communication, and speak slowly and softly. One family shared: He’s listening even though he’s not making eye contact. Pick up on how smart he is, but don’t assume that he understands everything. It’s the little things (language) that you may assume everyone gets, but he may not. If he isn’t getting your verbal direction, then show him a physical example. Understand that routines are important and this is far off his grid; if he’s not being compliant it doesn’t mean that he’s a bad kid. Explain what you’re going to do before you do it. Be honest. Go slow. Confirm he understands by having him repeat it back to you.

Families ultimately wanted to ensure that healthcare providers adjust to the child before them, and recognize the variable receptive and expressive communication needs of each individual with ASD. One family recommended the following, “To be willing to adapt how they do their job based on the person in front of them, not the model patient”. Many families recommended modeling and clearly communicating each step of a procedure.

Families wished that healthcare providers would take more time and be patient, and most importantly, listen and trust the knowledge of family members. As with their children with ASD, families wanted to help facilitate the medical visit but were frustrated when healthcare providers did not act upon their recommendations. One family stated, “Of course I would share medical history but also triggers that cause anxiety and behaviors. As well as information to decipher responses that might require additional context before making decisions on future care/medical treatment.” Another family stated, “I believe they should make all parts of a family involved in treatment, as well as the individual they are servicing”.

Autism Open Access, Vol. 10 Iss. 1 No: 247
Families wished that healthcare providers would better understand that behaviors, such as tantrums and aggressions, stemmed from the sudden change in routines and anxiety that comes from being in a new environment and people. Not knowing what was occurring and the lights, sounds, and touch and textures further escalated such behaviors. One family shared, “Mainstream providers tend to misread manifestations of ASD as poor behavior. Many seem oblivious to the potential sensory impact of their actions and procedures.”

**Medical environment:** As families shared, there are many environmental constraints in physical hospital buildings and with typical routines or protocol of such settings. Wait time and resources to provide entertainment and distractions were recommended by many families. Furthermore, families recommended that greater efficiency occur in terms of the number of people entering and exiting medical rooms decreasing the number of repeated medical history evaluations, and minimizing transitions from location to location.

Families also shared frustrations and trauma around a systemic issue -- the access to mental health and psychiatric floors. The lack of resources available led to immense trauma for both individuals with ASD and their families.

**Training and compassion:** Increasing knowledge through trainings was recommended by many families. Such awareness would minimize challenging behaviors, facilitate medical visits, and help healthcare providers be more patient and compassion. In turn, families and individuals with ASD would develop greater trust and comfort in medical professions. As one family stated: The diagnosis and characteristics are very different from person to person. In some situations, it is quite obvious that a person is autistic in other situations the person looks and acts typical. It is in these situations that health care providers need to have a better understanding of disability. It is important they understand strategies for dealing with OCD, anxiety, transitioning and behaviors that may impact a person from being comfortable and able to successfully communicate his or her needs.

In regards to these soft skills, a family also stated, “Compassion and empathy go a lot further than judgement and being harsh on a child you don’t know and don’t know what triggers they have.” Families did not want to experience glares or judgements due to their child’s reactions to the novel, frightening medical experience.

**DISCUSSION**

Identifying and developing rapport with a healthcare provider with knowledge and experience with caring for patients with ASD has a great impact in minimizing and preventing the fear, anxiety, and trauma families and individuals with ASD may experience. However, finding such healthcare providers involves actively seeking these professionals or obtaining care from providers within an ASD research institution. Families who have found healthcare providers who they can trust to care for their child feel fortunate, but recognized that the access is not equitable. Recognizing the challenges of medical care for this population, all families and individuals with ASD should experience patient-centered and family-centered care notwithstanding the quality of their healthcare policy or ability to pay out-of-network to access the medical professional with such experience.

Overwhelmingly, families shared that all healthcare providers must be increasingly knowledgeable and trained to provide care for patients with ASD. The rate in which individuals are identified as having ASD are growing and it is important that healthcare providers be responsive to the needs of this population. Harmful assumptions about the disability, and resources to help facilitate medical encounters are needed to ensure that this heterogeneous population is treated equitably in healthcare settings.

**The impact of knowledge and training**

Addressing the needs of the patient with ASD before you: Resoundingly, families wished that healthcare providers would recognize ASD is a spectrum disorder and providers must be responsive to the individual needs of the patient before them. Individuals with ASD may feel discomfort with the bright lights, noises, and smells of the hospital environment. Others may need weighted blankets and other sensory materials to remain calm or to distract them during long waits. Behaviorally, families wished that healthcare providers would understand of the antecedents of such behaviors, which may include anxiety, fear, illness, and other characteristics of ASD not being addressed. Reinforcers, such as stickers and tokens, coupled with praise and patience could help both healthcare providers and families facilitate medical visits.

**Presuming competence:** With little understanding of the heterogeneity of ASD, families wished that healthcare providers would understand that they must adjust to the communication needs of the patient. Using assistive technology, visual supports and schedules, task analyses, and social stories can all be useful resources the help facilitate communication between the patient with ASD and the healthcare provider. Families truly wanted healthcare providers to treat their child with respect, to understand and adapt in order to include their child in the medical encounter. From communication, to modeling a procedure, to allowing the patient to explore medical instruments, families wanted healthcare providers to take valuable time in facilitating medical visits for their oftentimes anxious and fearful child.

**Families as allies:** In addition to including the patient with ASD in the medical visit, families also wanted to play a greater role in facilitating the medical visit. Families shared that they wished healthcare providers would elicit information and recommendations on how best to address their needs of their child, and trust and listen to those recommendations to help make the medical encounter smoother.

**Developing compassion:** From these changes in practices, and interactions and experiences, healthcare providers may develop greater compassion for families of individuals with ASD. Instead of appearing annoyed or judgmental, greater empathy and understanding can be developed to help minimize or proactively prevent the trauma, anxiety, and fear many families shared and children with ASD experienced.

**LIMITATIONS OF THE STUDY**

The study included 40 survey responses. Though this is a small sample size, interpretive phenomenology allows for greater understanding of the unique experiences of these families. The survey asked families to recall situations and stories of medical encounters with their children with ASD. Retrospectively recalling such information may lead to some inaccuracies or families may not fully disclose these experiences. Therefore, it will be important for a follow-up interview or focus group to occur to help to further increase confidence in the survey responses provided in the study.
CONCLUSION

Through the examination of these responses, a greater understanding of the experiences, challenges, and unaddressed needs is developed. With individuals with ASD experiencing more medical encounters than neurotypical children and the increased in diagnosis rates, healthcare providers will encounter more patients with ASD. The current state of medical care is not responsive to the needs of this population and their families, which may have a prolonged impact on future medical care, as well as the educational and vocational success of individuals with ASD. The experiences and recommendations shared by families provides implications for healthcare providers and policy makers to develop more individualized medical care plans and reduce barriers to quality care across the lifespan.

Research and action are needed to further understand the unique perspectives of families and individuals with ASD on the quality of medical care. The heterogeneity of the population means that there are other unique experiences of families who wish to impart additional recommendations to support their child. Solution-based initiatives are needed in medical environments. Such initiatives must include training to increase knowledge, resources to facilitate medical visits, and a reflection and reconfiguration of the functioning of medical environments.

REFERENCES