

Understanding the Experiences and Barriers to Care Affecting Families of Children with Autism Spectrum Disorder (ASD)

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Abbreviations: Autism Spectrum Disorder (ASD), social determinants of health (SDOH)

Abstract

The national prevalence of ASD has shown a rising trend in recent years, specifically with a rise in cases diagnosed at younger ages in patients who identify as white, which may be due to progress in detection and increased surveillance in populations. Not all children are benefitting from this optimistic increase in early detection and intervention as ethnic disparities remain and certain minority groups continue to be disproportionately diagnosed at a later age despite similar clinical presentations to age-matched patients from other cultural backgrounds. Early therapeutic interventions are crucial for children to develop appropriate social, emotional and communicative behaviors. Consequently, children who are diagnosed later in life and face greater challenges in accessing treatment may have undesirable developmental outcomes. The purpose of this project is to identify potential sociocultural factors that may contribute to the disparities that exist. Although the factors influencing disparities may be multifactorial, this study focuses specifically on the level of acculturation and social determinants of health as quantitative measures. While also considering perspectives of the diagnostic process from the families of children with ASD reported as qualitative findings. Participants completed a mixed-mode online survey instrument, available in English and Spanish, that investigated potentially problematic barriers influencing delays in diagnosis and limited access to treatment. The goal of this study is to better understand the experiences that families encounter and identify important predictors that a child with ASD will have difficulty in obtaining adequate care.

Introduction

The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) provides diagnostic criteria for Autism Spectrum Disorder (ASD)². The standardized measures include deficits in social-emotional reciprocity, nonverbal communicative behaviors as well as deficits in developing, maintaining, and understanding relationships⁷. Diagnosing ASD is challenging due to heterogeneity in symptom presentation as well as onset of signs in development and lack of biologic diagnostic markers⁴. For this reason, it is crucial for families to work closely and openly with the child's care team in order to recognize behaviors as early as

possible to implement appropriate intervention. It was estimated that ASD prevalence has increased from 1 in 59 in 2018 to 1 in 44 children for 2021, which suggests there may be progress in the identification of this disorder with awareness and screening⁵. The most recent reports have found that on average children are being diagnosed after age 4 even though Autism can be reliably diagnosed as early as 2 years old⁵. However, ethnic disparities remain prevalent among minority communities as they continue to be disproportionately diagnosed at a later age despite similar clinical presentations to age-matched patients from other cultural backgrounds and receive fewer evidence-based treatments^{7,1}.

There has been less focus on the specific patient and family factors contributing to ASD diagnostic disparities with few studies examining the particular barriers experienced and subsequent treatment use among minority families⁷. This study focused on the timeliness of diagnosis and introduction of therapy services offered while considering SDOH and level of acculturation as potential barriers. Additionally, inquiring if the needs of the child are being met from a family's perspective.

Clinically, it is vital to consider multiple sociocultural factors that may influence a family's beliefs and understanding about a new diagnosis of ASD and initiation of treatment. Culture may also impact diagnosis through societal beliefs and expectations regarding a child's natural behavioral development. Thus, differences in such beliefs can be barriers to health-seeking behaviors, utilization, prevention and treatment⁹. A notable barrier for less acculturated families has been the lack of parent knowledge about ASD which means these families will encounter more difficulty when seeking information about the diagnostic process, devising treatment plans and navigating the healthcare system⁷. Consequently, these families can experience disproportionate barriers associated with more unmet needs⁷.

The objective of this study is to use a mixed-mode online survey to better understand the experiences of families of children with autism spectrum disorder (ASD) regarding delays in diagnosis and subsequent barriers in obtaining access to care. This study investigated the level of acculturation of the parents/guardians and identified if social determinants of health (SDOH) impacted their access to adequate care and timeliness of intervention. We also explored the parent's perspective on what areas have proven to be the greatest challenge during the diagnostic and therapeutic process reported as general recurring themes. We focused on the timeliness in receiving a diagnosis, accessing treatment and meeting the goals of the children. The survey incorporated a modified questionnaire detailing the diagnostic process, current therapy services provided, acculturation scale, social needs screening and parental background. We hypothesized that based on the mixed-mode survey instrument, the families of children with ASD with lower levels of acculturation and greater number of social needs will have encountered greater than average obstacles when obtaining proper diagnosis and adequate care. Thus, there is expected to be delay in diagnosis and subsequent access to care for the child. This outcome is expected to further stress the importance of early intervention and implement more effective communication strategies when interacting with patients of different cultural backgrounds.

Methods

The aim of this study is to assess several factors that may influence the diagnostic process and subsequent access to treatment for a child with ASD while exploring the families' social determinants of health and level of acculturation as potential barriers. We conducted a cross-

sectional survey that was made available online with attached informed consent. All survey measures were available in English and Spanish. The survey had been developed and adapted based on the Oregon Health and Science University (ASD) survey with permission granted by Dr. Katherine Zuckerman and Social Determinants of Health (SDOH) screening tools provided by the American Academy of Family Physicians (AAFP) and the Short Acculturation Scale for Hispanics (SASH)¹².

Subjects

Parents/guardians who identify as families of children with a confirmed diagnosis of ASD were eligible to participate in this study.

Survey Development

Since no validated survey existed for family-reported measures of barriers to ASD care, the Oregon Health and Science University (ASD) survey was created by Dr. Zuckerman who adapted her survey based on the 2009/2010 National Survey of Children with Special Health Care Needs, the US Census American Community Survey as well as the 2011 Survey of Pathways to Diagnosis and Services. Modifications were made with her permission using additional validated surveys that aligned with the direction of this specific study⁷. We added the Short Acculturation Scale for Hispanics (SASH) and several screening questions that investigate social needs based on the AAFP's SDOH questionnaire^{8,10}. The SASH questionnaire was filled out by the 2 participants who identified as Hispanic and were therefore prompted to fill out SASH acculturation tool. The average was calculated across 4 questions, where a score above 2.99 represents higher levels of acculturation, anything less than 2.99 represents low levels of acculturation. The Social Needs screening includes questions about housing, food, transportation, utilities, child care, employment, education and finances, where certain answer choices represent a positive response for a social need for the given category. Additionally, two free response questions were added to allow caregivers to detail their experiences in their own words and provide qualitative measures. The survey had been translated into Spanish as well to allow for more inclusive participation. Together these measures provided a better assessment regarding the overall experience of families in terms of barriers in diagnosis, therapy use and satisfaction with the child's progress and future ambitions.

Survey Distribution and Completion

Institutions and organizations that support the health and well-being of people affected by Autism were contacted prior to distribution of the survey. Snowball sampling was also used to reach a larger audience. Once participants consented to participating in the research and all potential risks had been identified, the survey was made available electronically in either Spanish or English. At the conclusion of the study 7 study participants completed their survey. Though low sample size provides limited power to detect statistically significant results in a number of circumstances, the statistical analyses revealed statistically significant and substantively important results relevant to the research question and existing research in this area.

Tables of descriptive statistics

Table 1. Table of Survey Participant Demographic Characteristics

Table of Survey Participant Demographic Characteristics					
Variable	N	Mean/Proportion	SD	Min	Max
Age	6	46.83333	19.85363	27	79
Gender (Female)	7	1	0	1	1
Relationship to Child					
<i>Parent</i>	7	0.8571429	0.3779645	0	1
<i>Grandparent</i>	7	0.1428571	0.3779645	0	1
Hispanic/Latino	7	0.7142857	0.48795	0	1
Race/Ethnicity					
<i>White</i>	7	0.5714286	0.5345225	0	1
<i>Black/African American</i>	7	0.1428571	0.3779645	0	1
<i>Other</i>	7	0.1428571	0.3779645	0	1
<i>Multi-Race/Ethnicity</i>	7	0.1428571	0.3779645	0	1
English Proficiency	7	1	0	1	1
Low SASH	7	0.2857143	0.48795	0	1
Social Needs	7	3.285714	1.603567	1	6

Table 2. Table of Survey Participant Beliefs and Perceptions About ASD Statistics

Table of Survey Participant Beliefs and Perceptions About ASD Statistics					
Variable	N	Mean/Proportion	SD	Min	Max
Autism Health Worker Helpful	7	0.8571429	0.3779645	0	1
Autism Parent Advocate Helpful	7	1	0	1	1
Same Worker/Advocate Ethnic Background Helpful	6	0.5	0.5477226	0	1
ASD Is Lifelong	7	1	0	1	1
ASD Has Major Consequences	7	0.8571429	0.3779645	0	1
ASD Is a Mystery to Me	7	0.5714286	0.5345225	0	1
Connection Between Vaccinations and Autism	7	0.2857143	0.48795	0	1
Community Has Little Knowledge About ASD	7	0.8571429	0.3779645	0	1
Community Thinks ASD is Only in US	7	0.1428571	0.3779645	0	1
Best Ways to Help Spread Info About ASD					
<i>TV, Radio & Newspapers</i>	7	0.5714286	0.5345225	0	1
<i>Doctor's Office Info</i>	7	0.1428571	0.3779645	0	1
<i>Doctor and Nurse Guidance</i>	7	0.8571429	0.3779645	0	1
<i>Doctors and Nurses Become More Knowledgeable</i>	7	0.4285714	0.5345225	0	1
Best Ways to Improve ASD Diagnoses					
<i>Explanations From Clinics</i>	7	0.5714286	0.5345225	0	1
<i>Checklists from Doctors and Nurses</i>	7	0.5714286	0.5345225	0	1
<i>Faster Doctor and Nurse Action</i>	7	0.8571429	0.3779645	0	1

Table 3. Table of Survey Participant Diagnostic Experience Statistics

Variable	N	Mean/Proportion	SD	Min	Max
Knew A Lot About ASD	7	0	0	0	0
Difficulty Understanding Medical System	6	1	0	1	1
Difficulty Trusting Doctors/Nurses	6	0.5	0.5477226	0	1
Needed to See Multiple Providers for Diagnosis	7	0.7142857	0.48795	0	1
Had to Repeatedly Express Concerns	7	0.8571429	0.3779645	0	1
ASD Evaluation Was Quick	7	0.2857143	0.48795	0	1
ASD Evaluation Was Expensive	7	0.8571429	0.3779645	0	1
Medical Interpreters Were Available	7	0.1428571	0.3779645	0	1
Doctor's Attributed Problems to Language at Home	7	0.1428571	0.3779645	0	1
Doctor Shared Same Race/Ethnicity	7	0.5714286	0.5345225	0	1
Language Barrier With Doctor	7	0.1428571	0.3779645	0	1

Table 4. Table of Demographic Statistics for Survey Participant's Child with ASD

Variable	N	Mean/Proportion	SD	Min	Max
Age	7	11.9881	10.49906	2	28.16667
Gender (Female)	7	0.4285714	0.5345225	0	1
Hispanic/Latino	7	0.2857143	0.48795	0	1
Race/Ethnicity					
<i>White</i>	7	0.5714286	0.5345225	0	1
<i>Black/African American</i>	7	0.1428571	0.3779645	0	1
<i>Other</i>	7	0.1428571	0.3779645	0	1
<i>Multi-Race/Ethnicity</i>	7	0.1428571	0.3779645	0	1
ASD Severe	7	0.2857143	0.48795	0	1
Age First Noticed Something Wrong	7	1.869048	0.9152225	0.9166667	3.5
Insurance Coverage Type					
<i>Through Employer or Union</i>	7	0.5714286	0.5345225	0	1
<i>Medicaid</i>	7	0.7142857	0.48795	0	1
<i>Other</i>	7	0.1428571	0.3779645	0	1
<i>Unsure</i>	7	0.1428571	0.3779645	0	1

Table 5. Table of Therapy Experience Statistics for Survey Participant's Child with ASD

Table of Therapy Experience Statistics for Survey Participant's Child with ASD					
Variable	N	Mean/Proportion	SD	Min	Max
COVID Posed Challenges	7	0.8571429	0.3779645	0	1
Hours of Therapy Received Per Week (Home)					
None	7	0.5714286	0.5345225	0	1
1-4 Hours	7	0.1428571	0.3779645	0	1
11-20 Hours	7	0.2857143	0.48795	0	1
Hours of Therapy Received Per Week (School)					
None	5	0.2	0.4472136	0	1
Less than 1 Hour	5	0.2	0.4472136	0	1
1-4 Hours	5	0.2	0.4472136	0	1
5-10 Hours	5	0.2	0.4472136	0	1
More than 20 Hours	5	0.2	0.4472136	0	1
Medications/Treatments					
Prescriptions	7	0.4285714	0.5345225	0	1
OTCs	7	0.2857143	0.48795	0	1
Dietary Treatments	7	0.1428571	0.3779645	0	1
Vitamins	7	0.5714286	0.5345225	0	1
Herbal Supplements	7	0.1428571	0.3779645	0	1
None	7	0.2857143	0.48795	0	1

Table 6. Table of Therapy Outcome Statistics for Survey Participant's Child with ASD

Table of Therapy Outcome Statistics for Survey Participant's Child with ASD					
Variable	N	Mean/Proportion	SD	Min	Max
Age at Diagnosis	7	2.928571	3.194117	1	10
Diagnosis Gap	7	1.059524	2.405007	0	6.5
Age When Starting Therapy	7	5.809524	7.739048	1	23
Therapy Gap	7	2.880952	4.683219	0	13
Receives Therapy Weekly	7	0.7142857	0.48795	0	1
Able to Start Therapy Quickly	7	0.5714286	0.5345225	0	1
Receives All of the Therapy Needed	7	0.2857143	0.48795	0	1
ASD Challenges Can Be Reduced With Treatment	7	0.8571429	0.3779645	0	1

Statistical analysis

Due to low sample size limiting the ability to carry out statistical analysis involving more than two categories, the categorical and ordinal measures in the survey were transformed into dichotomous ones for analyses. The analysis used include Spearman Rank Correlation, Fisher's exact test and a Cramer's V measure of association.

Results

The sections that follow start with a focus on the SASH and social needs that are of primary interest to this research project before then turning to other findings tied to previous research on this subject matter.

The first analysis discussed here (and found below) is a Spearman Rank Correlation analysis that examines the association between the age when a child diagnosed with ASD was first brought to a doctor or nurse and the number of social needs the parent/guardian of the child possessed. The results here show a strong (and statistically significant) negative association between these two factors, wherein greater social needs of parents/guardians are associated with talking to doctors/nurses about their child and ASD at younger ages.

Number of obs = 7
Spearman's rho = -0.7963

Test of H0: Q4years and socneeds are independent
Prob > |t| = 0.0321

The second set of analyses below include a Fisher's exact test (which was used instead of a Chi-square test due to the low sample size) and a Cramer's V measure of association, which together examine the relationship between the dichotomous measure of low vs. high SASH and the dichotomous measure of agreement vs disagreement with the statement that their ASD child receives all the therapy they need. The Fisher's exact p-value of less than .05 indicates that there is a statistically significant relationship between these two factors, while the Cramer's V indicates that, in fact, there is a perfect positive association between them, wherein low SASH is associated with the belief that their children receive all the therapy they need.

sashlow	Q14_2agree		Total
	0	1	
0	5	0	5
1	0	2	2
Total	5	2	7

Cramér's V = 1.0000
Fisher's exact = 0.048
1-sided Fisher's exact = 0.048

The last set of analyses focus on the age of the child diagnosed with ASD.

The first of these analyses is a Spearman Rank Correlation analysis that examines the association between the current age of the child diagnosed with ASD (when the survey was taken) and the age when they started using any type of therapy services. The results here show a strong (and statistically significant) positive association between these two factors, wherein older age is associated with a later starting age for using therapy services.

Number of obs = 7
Spearman's rho = 0.8829

Test of H0: Q15years and Q25years are independent
Prob > |t| = 0.0085

The second of these analyses is a Spearman Rank Correlation analysis that examines the association between the current age of the child diagnosed with ASD (when the survey was taken) and the gap (in years) between when they first met with a doctor/nurse regarding in

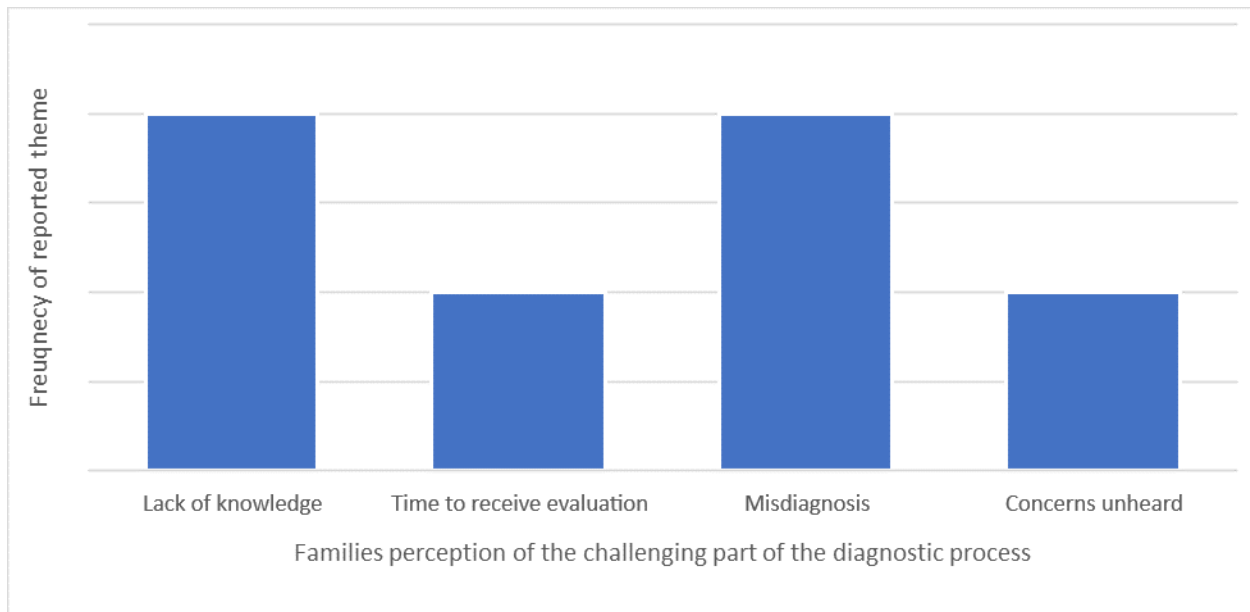
relation to ASD and when they started receiving any type of therapy services. The results here show a strong (and statistically significant) positive association between these two factors, wherein older age is associated with a larger gap between when children first met with a doctor/nurse and when they eventually start receiving therapy services.

Number of obs = 7
 Spearman's rho = 0.8289
 Test of H0: therapy_gap and Q25years are independent
 Prob > |t| = 0.0212

Qualitative trends

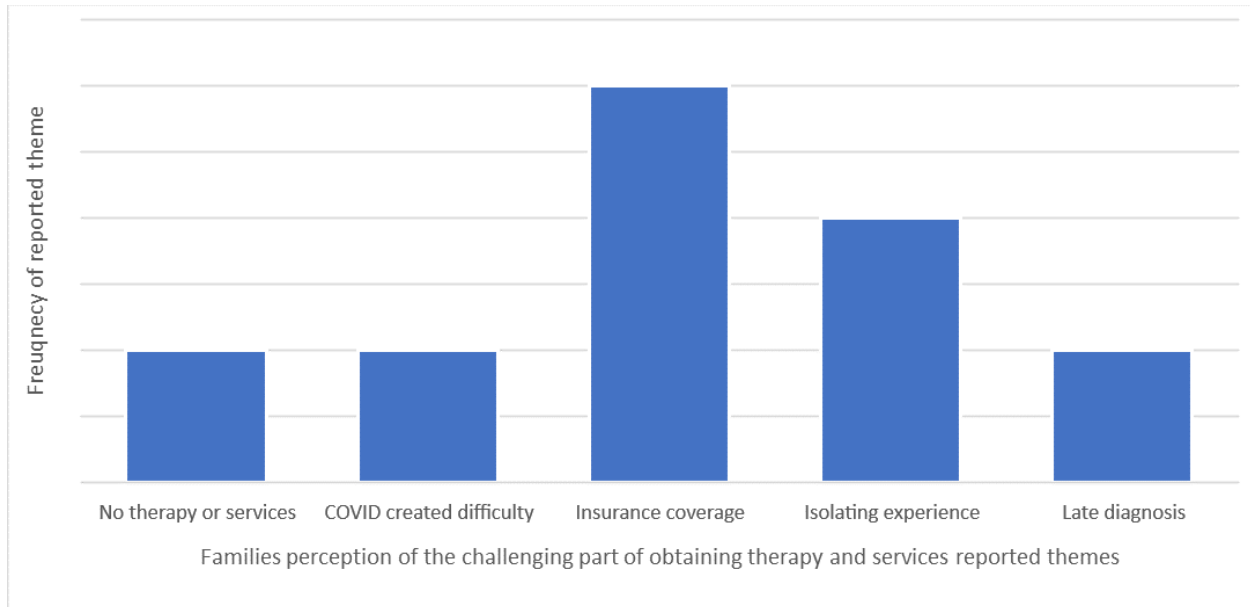
There were two open ended questions incorporated in the survey. The families of children with ASD were allowed to provide their opinion on what they believed to be the most challenging part of the diagnostic process and obtaining services in a free response format. The open ended answers were analyzed and if repetitions were identified they constituted a theme. The greater recurrence of themes were then interpreted to be significant barriers for the subset of participants¹³. A histogram was created to provide a visual representation of the most frequently reported themes in the families comments.

Table 7. Families of children with ASD perception of the most challenging part of the diagnostic process



Across all of the comments one can appreciate that from a families perspective, the “lack of knowledge” and “misdiagnosis” proved to be the frequent answer provided when asked about most prominent challenges in the diagnostic process.

Table 8. Families of children with ASD perception of the most challenging part of obtaining therapy and services



Across all of the comments one can discern that insurance coverage was repeatedly mentioned as the most challenging part in obtaining therapy and services. Another notable challenge was how “isolating” the overall experience has been for children with ASD.

Discussion

The research surveyed the diagnostic process and therapeutic intervention for children with ASD while exploring families’ level of acculturation and social determinants of health as potential barriers to care. It was hypothesized that the families of children with ASD with lower levels of acculturation and more social needs will have encountered greater barriers in obtaining timely diagnosis and adequate care. Although our research did not provide results that necessarily supported this hypothesis, our findings did provide statistically significant data and valuable information that was both supported by prior research and challenged existing ideas. Ultimately, providing insight into gaps between parents and the healthcare system when advocating for children with ASD.

The research concluded that greater social needs based on the SDOH screening were associated with families’ talking with medical providers about their child and ASD at younger ages. This highlights an important concept, despite families facing more social needs, the awareness and inclination to report concern is demonstrated at an earlier age. Prior studies have identified that SES contributes to disparities in ASD knowledge, as well as diagnosis and access to care ¹¹. Most research suggests that ASD-associated features are not recognized or acknowledged by parents until they interfere later on in life. However, our research challenges this idea, therefore ASD concerns should be closely examined for all families regardless of their SES status. Although several factors may impede access to care, a family’s SES status should not be one of them.

It was also found that low acculturation levels based on the SASH screening were associated with the belief that the children were receiving the appropriate therapies from a family's perspective. Existing research has reported that cultural influences can shape perceptions of development and disability and may contribute to discrepancies in ASD particularly for families of low acculturation ¹¹. Our particular finding has not yet been highlighted in existing literature but highlights the need for cultural sensitivity that may bridge the gaps between patients and healthcare workers.

Also, when examining the age of the child diagnosed, the results found that an older age is associated with a larger gap between when children first met a medical provider and when they initiated therapy services. This proves to be of significant importance as we know that early detection is crucial as initiating intensive behavioral intervention improves learning, communication and social skills in young children with autism spectrum disorders (ASD) ⁵. Interestingly, the qualitative results that will be discussed later also noted that misdiagnosis and lack of knowledge were the most challenging part of the diagnostic process for families. This puts further emphasis on how misdiagnosis contributes to children being diagnosed at an older age and raises the concern for late intervention.

Qualitatively the results demonstrate that across all comments one can discern frustration with the time and obstacles that confronted caregivers in receiving a diagnosis and obtaining services. Previous studies have identified that the stress of the diagnostic process proves to be a predominant barrier to care but less research has examined what factors of the diagnostic process prove to be most challenging ⁷. The families surveyed identified similar challenges, expressing a lack of knowledge in the diagnostic process and reported similar frustrating experiences with misdiagnosis. This finding provides additional reasoning as to why early and correct identification of ASD is critical especially given the documented importance of early intervention. When it comes to challenging aspects of obtaining services, families similarly reported difficulty with obtaining insurance coverage and also described the process to be an isolating experience. From these results we can identify significant barriers and areas to be addressed by the healthcare team to help the families of children with ASD. Regardless of SES and level of acculturation, from these answers we can identify shared challenges and experiences thus providing insight into how to best close the diagnostic gap and improve treatment outcomes for ASD children.

Various limitations to this study were identified throughout the development of the research project. The study was conducted during a global pandemic which led us to solely depend on an online based format which further limits the availability and access of this survey to those with internet capabilities. It is also believed that the length of the survey discouraged participants from completing the survey thus limiting the sample size. Of the 12 participants that began the survey only a total of 7 participants completed it in its entirety. Additionally, we used a snowballing technique hoping to reach a larger audience and despite connecting with notably recognized Autism support groups the timeliness of the pandemic created obstacles in the dissemination of information. In the future, it would be helpful to consider focus groups for the families of children with ASD to collect more substantial qualitative research regarding their experiences and beliefs on the subject matter.

The aim of this study was to bring awareness to the issues that families are faced with when experiencing barriers to proper ASD care. The goal was to identify the obstacles that arise and determine how they can be addressed in order to provide families of ASD children with the optimal care plan designed for long term success. Research in the area can help to promote better understanding of the sociocultural factors affecting ASD knowledge and how important it is for successful health promotion ¹¹. Continued surveillance on this issue is an urgent public health concern since early intervention will allow for the healthiest development and provide the most benefit across the lifespan ⁵. Understanding how and why the disparities exist will lead to enhancing strategies to identify ASD even earlier and address the various needs of this population.

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