



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

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Introduction

The national prevalence of ASD has shown a rising trend in recent years however, ethnic disparities remain, and minority groups continue to be disproportionately diagnosed at a later age despite similar clinical presentations to age-matched patients from other cultural backgrounds. 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. Although the factors influencing disparities may be multifactorial, this study focuses specifically on the level of acculturation and social determinants of health (SDOH) as independent variables impacting age of diagnosis and access to care. Also of interest is the perspectives of families on the diagnostic process from the families of children with ASD.

Research Question

Our research question explored the impact of SDOH and acculturation on the ability of minority families to access diagnosis and treatment for children with ASD. We hypothesized the families of children with ASD with greater number of social needs and lower levels of acculturation will have encountered greater than average obstacles when obtaining proper diagnosis and adequate care. This research advocates for early intervention and the implementation of more effective communication strategies for families of children with ASD.

Materials and Methods

We conducted a cross-sectional survey available in English and Spanish, that investigated barriers in diagnosis and access to treatment for families of children with ASD. The survey included a modified questionnaire detailing the diagnostic process, current therapy services provided, acculturation scale (SASH), social needs screening and free response questions detailing parent's experiences and perceptions about the greatest barriers to care. Institutions and organizations that support the health and well-being of people affected by Autism were contacted and snowball sampling was also used to reach a larger audience.

The statistical analysis used for the quantitative data included Spearman Rank Correlation, Fisher's exact test and a Cramer's V measure of association. For the qualitative data examining the two open ended questions included in the survey, we analyzed the responses and themes were identified in repetitious elements found within and across responses. Repetitive thematic elements pointed to significant barriers experienced by respondents. A histogram provides a visual representation of the results.

Results

At the conclusion of the study 7 participants completed their survey. This research concluded that greater social needs of parents based on the SDOH screening are associated with expressing concerns about their child and ASD to providers at age younger than the age at diagnosis. This was based on Spearman's rank correlation analysis which found a negative association (Spearman's rho= -0.7963) between these two factors.

The second set of analyses using a Fisher's exact test report a p-value of less than .05 and a Cramer's V measure of association, which together examine the relationship between the dichotomous measure of low vs. high acculturation and the measure of agreement vs disagreement with the statement that their ASD child receives all the therapy they need. We 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.

The last set of analyses was based on Spearman's rank correlation analysis which found a positive association (Spearman's rho= 0.8982) between these two factors, wherein children who were diagnosed at an older age had a larger gap from the time of their diagnosis to when they start receiving therapy services.

Qualitative results gathered from open ended questions in the survey found that across all of the comments one can appreciate that from a families' perspective, the "lack of knowledge regarding the diagnostic process" and "misdiagnosis" proved to be the most prominent challenges during the diagnostic process. Also, families reported that adequate "insurance coverage" was the most significant barrier in obtaining proper care in addition to describing the experience as "isolating."

Table 1. Table of Survey Participant Demographic Characteristics. Where "Low SASH" is based on the level of acculturation scale and "Social Needs" is the number of SDOH identified in the questionnaire.

Variable	N	Mean/Proportion	SD
Age	6	46.83333	19.85
Gender (Female)	7	1	0
Relationship to Child			
Parent	6	0.8571429	0.378
Grandparent	1	0.1428571	0.378
Hispanic/Latino	7	0.7142857	0.488
Race/Ethnicity			
White	7	0.5714286	0.53
Black/ African American	7	0.1428571	0.378
Other	7	0.1428571	0.378
Multi-Race/Ethnicity	7	0.1428571	0.378
English Proficiency	7	1	0
Low SASH	7	0.2857143	0.488
Social Needs	7	3.285714	1.6

Table 2. Table of Therapy Outcome Statistics for Survey Participant's Child with ASD

Variable	N	Mean/Proportion	SD	Min	Max
Age at Diagnosis (years)	7	2.928571	3.19	1	10
Diagnosis Gap (years)	7	1.059524	2.41	0	6.5
Age When Starting Therapy (years)	7	5.809524	7.74	1	23
Therapy Gap (years)	7	2.880952	4.68	0	13

Table 3. Families of children with ASD perception of the most challenging part of the diagnostic process

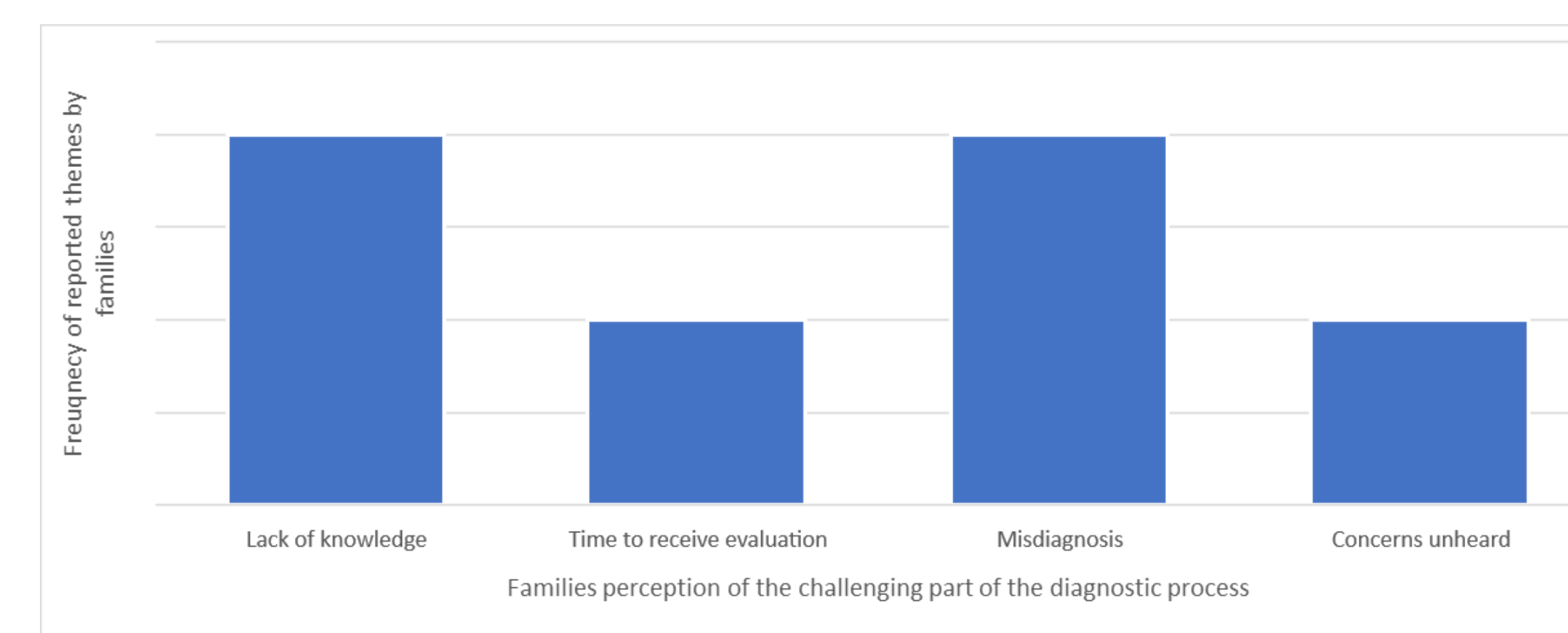
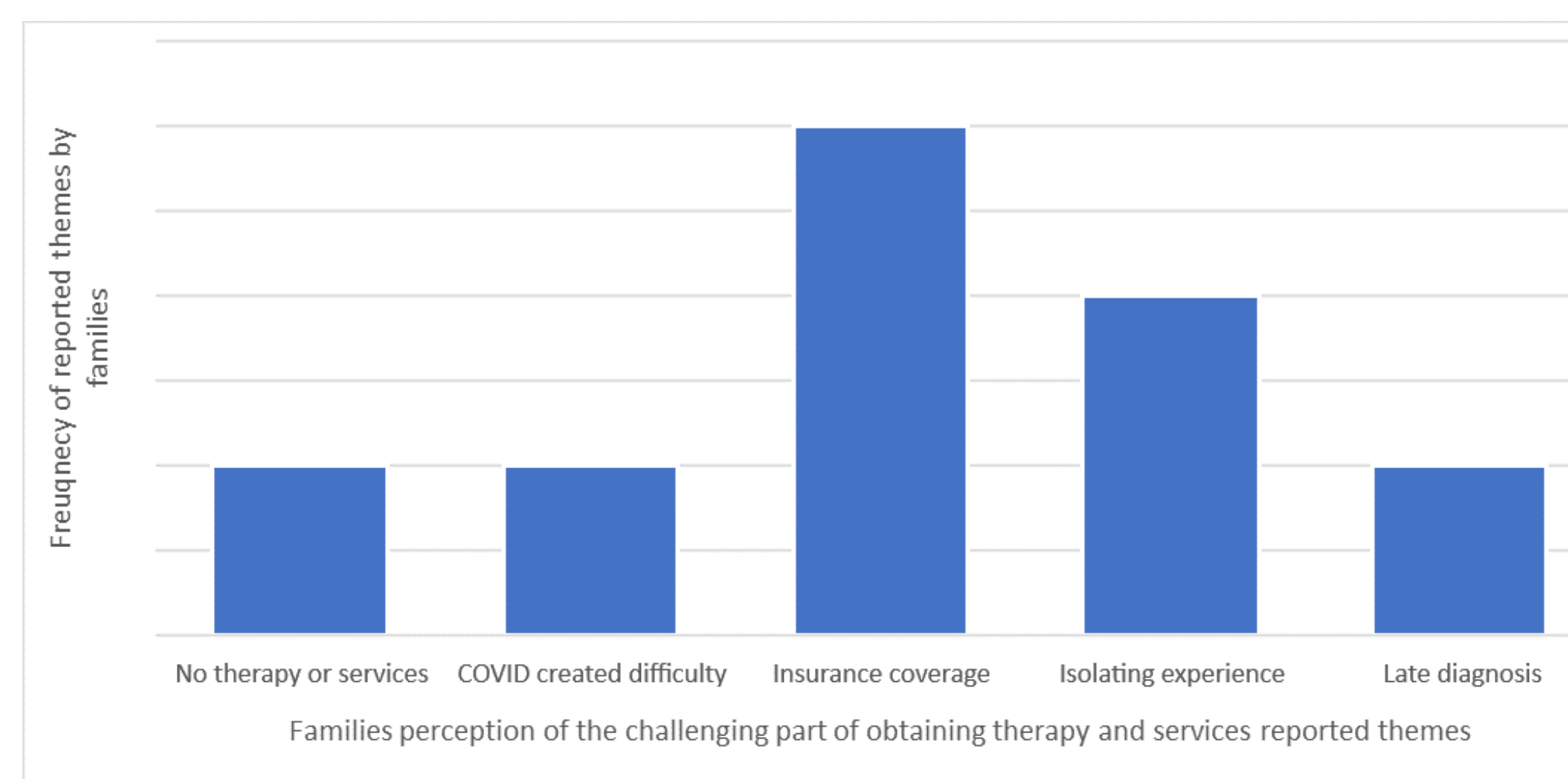


Table 4. Families of children with ASD perception of the most challenging part of obtaining therapy and services



Conclusion

The research surveyed the diagnostic process and therapeutic interventions for children with ASD while exploring families' level of acculturation and social determinants of health as independent variables and potential barriers to care. The research concluded that despite facing greater social needs, families raised concerns for ASD features with medical providers at younger ages. Yet, expressed concerns did not yield early diagnoses for respondents. Existing research suggests that ASD-associated features are not recognized until much later by families; however, our research challenges this idea. Our results also reveal that barriers in diagnosis stems from factors other than families' awareness of signs of developmental delay. In fact, families report that misdiagnosis and insurance issues to be the true barriers in obtaining a timely diagnosis and subsequent access to care. Additionally, children who are diagnosed at a later age experience a larger gap between when first meeting a provider and when they initiate therapy services. This further emphasizes how misdiagnosis contributes to children being diagnosed at an older age and raises the concern for late intervention. Also, families with lower acculturation levels were associated with the belief that the children were receiving the appropriate therapies. Conducting research online during a global pandemic proved challenging and relying on internet access for the survey creates a barrier for populations. In the future, it would be helpful to consider focus groups for families and providers to collect data regarding their experiences and insight into what contributes to diagnostic delays.

Summary

- Barriers in diagnosis stem from factors other than families' awareness of developmental delays as those with greater social needs demonstrate early awareness and concerns raised with providers yet it does not yield early diagnoses.
- Misdiagnosis and insurance issues prove to be significant barriers on the ability of minority families to access diagnosis and treatment for children with ASD.
- Understanding how and why disparities persist will lead to enhancing strategies to identify ASD earlier and address the needs of this population.

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