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Stigma and Service Utilization around Autism Spectrum Disorder in Underrepresented Ethnoracial Minority Groups

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ABSTRACT

Numerous services and interventions are available to support families affected by autism spectrum disorders, However, there are many inequities present in the different households of autistic children or adults, with several factors related to these inequities in different racial or ethnic groups. Specifically, negative stigma towards autistic children can be a significant sociocultural barrier impacting service access, as the decisions around services may depend on differing views according to their traditions, cultural beliefs and practices, leading to diverse approaches in understanding and managing the condition. This study examines the role of stigma in service utilization among underrepresented ethnoracial minority groups, focusing on South Asian, Middle Eastern, North African, and East African families. It was hypothesized that higher stigma is related to lower use of autism-related services. Data from 52 parents were analyzed to explore this relationship, revealing that stigma may significantly impacts service utilization but this is dependent on service type, highlighting the need for culturally sensitive approaches to reduce health disparities and improve access to autism-related services.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects the development of people by affecting their interactions and behaviors (American Psychiatric Association, 2013). Autistic individuals experience a multitude of challenges. These challenges include trouble communicating with others, differences in learning, and sensory issues, as well as mental health issues like depression and anxiety. To address these challenges, there is a wide range of services and interventions available to families affected by ASD (Kang et al., 2022). However, ethnoracial minority groups often receive less treatments and interventions compared to non-minority groups, including those affected by ASD (Magaña et al., 2012; Zeleke, Hughes, & Drozda, 2019).

One of the sociocultural factors that can play a huge role in impacting access to services is negative stigma towards autistic children. Stigma is defined as a socially constructed notion that describes the situation of the "individual who is disqualified from full social acceptance" (Goffman, 1963, p. 9). Cultural norms appear to be closely linked to stigma (Mitter, Ali, & Scior, 2019). Cultural attitudes towards autism vary, with some cultures, particularly Asian, viewing it more negatively due to strict social norms, whereas American and European cultures tend to have a more accepting view of autism. Indeed, a systematic review revealed that stigma-related experiences in family members of autistic children often depend on family culture, which can lead to family members' social withdrawal and isolation (Mitter, 2019). For instance, immigrant mothers in the United States report feelings of isolation due to the stigma surrounding ASD, along with a desire for community acceptance of their children. Additionally, these mothers sometimes face suspicions of child neglect from their community (Ijalba, 2016). Therefore, it is plausible that stigma also affects healthcare services, as the perceived familial shame can restrict healthcare access and create reluctance to discuss the issue, thereby limiting the exploration of available services (Sakai et al., 2019). For instance, the diagnosis of disabilities within collectivist cultures often encounters delays, particularly for ASD, leading to social isolation as families may refrain from disclosing their child's condition (Kim et al., 2020; Rivard, 2019).

Stigma relating to patterns of service utilization is important. This is because different levels of stigma have a profound effect on the services that are utilized. For example, increased stigma would decrease service utilization, and vice versa. This study will be focusing on examining the role of stigma in service utilization in underrepresented ethnoracial minority groups. Among the ethnoracial minority groups, there is very little information known about families from South Asia, Middle Eastern and North Africa (MENA), and East African groups, and there is a relative lack of responsivity from this group in health disparity research (Mukherjea et al., 2018). Therefore, it is important to include these groups in autism-specific health disparity research, as many studies have not focused on these underrepresented ethnoracial minority groups.

Current Study

This study aimed to examine the relationship between parent's stigma about autism and types of services families are receiving, including auxiliary services. It was hypothesized that higher stigma endorsed by families will be related to lower use of frequently-used ASD-related services.

Methods

Participants

Fifty-two parents of autistic individuals aged 3-21 completed the study. Participants were recruited via word of mouth, social media platforms, community centers, and faith-based organizations. Participants completed an online REDCap survey (average completion time ~ 30 minutes) in English which included a consent form and questionnaires in accordance with the University Institutional Review Board-approved procedures. See Table 1 for Participant Demographic information.

Table 1. Parent and Child Characteristics

Parent characteristics		
Age (in years)	*M* = 41.3	*SD* = 5.9
	n	%
Gender		
Female (biological mother)	47	90.4
Race		
South Asian	40	76.9
MENA	8	15.4
East African	4	7.7

Child characteristics		
Age (in years)	*M* = 11.0	*SD* = 4.6
	n	%
Gender		
Male	41	78.8
Current education level		

Kindergarten	7	13.5
Elementary	18	34.6
Middle	11	21.1
High	10	19.2
College	1	1.9
Not in school	2	3.8
Other	3	5.8
School		
Public	42	80.8
Private	4	7.7
Special Needs	5	9.6
Other	1	1.9
Primary Diagnosis		
ASD	52	100

Measures

Autism Stigma and go Knowledge Questionnaire (ASK-Q; Harrison et al., 2017)

The ASK-Q was originally created to capture the global literature on ASD knowledge and facilitate cross-cultural research. It consists of 49 items with response options of “Agree,” “Disagree,” or “Don’t Know.” The questionnaire addresses four key areas of ASD-related knowledge: diagnosis/symptoms, etiology, treatment, and stigma. For the present study, only the questions related to stigma were utilized. Responses marked as “agree” were scored as 1, while “disagree” and “don’t know” responses were scored as 0.

Background Questionnaire

This questionnaire collected data on participant demographics and the utilization of autism-related services. It assessed the specific treatment approaches used by families, including auxiliary and developmental services. The comprehensive list of autism-related services was developed based on descriptions from the literature and information available on websites maintained by advocacy groups like the Autism Society of America, as well as various state agencies across the country (Thomas et al., 2006). Additionally, it included more recent interventions such as social skills training (Kang et al., in press; McDonald et al., 2022). Service use by family was determined dichotomously by “Yes” or “No” reported by each participant’s caregiver.

Data Analytic Plan

Frequency was used to assess services that were frequently used by families. Point-biserial correlations was used to examine the relationship between stigma and whether or not they are using the frequently used services.

Results

The most frequently-endorsed services used by families in the current sample were (in the order of decreasing frequency): Applied Behavioral Analysis (ABA), Speech Therapy (SP), Occupational Therapy (OT), Physical Therapy (PT), Music Therapy, and Adaptive Physical Education.

Parent’s score of autism stigma was related to receiving Physical Therapy ($r_{pb} = .305$, $p < 0.05$), such that higher stigma was related to endorsement of receiving physical therapy. Level of stigma did not relate to other aforementioned frequently-used intervention approaches (all $p > 0.05$; Table 2).

Table 2. Point Biserial Correlations between Stigma and Intervention Types

Intervention Type	
1. Applied Behavioral Analysis	.11
2. Speech Therapy	-.11
3. Occupational Therapy	-.06
5. Physical Therapy	**.34***
6. Music Therapy	.08
7. Adaptive Physical Education	-.04

*. Correlation is significant at the 0.05 level (2-tailed).

Discussion

This study was one of the first studies to examine the relationship between parent's stigma around autism and whether or not specific treatment approaches will be used in a sample of ethnoracial minority groups. Particularly, this study represents first of its kind to specifically examine the relationship with stigma endorsed by parents and the use of most frequently-used services and interventions in South Asians, MENA, and East Africans.

While families affected by ASD use a wide range of services, ABA, and allied services commonly provided with students with special education (ST, OT, and PT), along with music therapy and adaptive physical education, were some of the most frequently-used services in the current study sample. This is consistent with previous reports in broader autism field in that services suggested by providers, schools, and those funded by private and state-funded insurance agencies tend to be the most commonly accessed (Alban Havens, 2019). Moreover, the findings are also partly consistent with prior works suggesting speech therapy as the most utilized service in schools and is considered one of the best services by parents, followed by occupational therapy (Thomas, Morrissey, & McLaurin, 2006).

However, contrary to the literature on general literature in ASD that suggests social skills training as one of the intervention approaches that are being widely used for autistic youth (McDonald et al., 2022; Thomas et al, 2006), social skills training was not one of the frequently-used approaches in this sample. A potential explanation for this includes that access to services in families in these ethnoracial minorities may mostly depend on generalized service availability like the insurance payment for ABA; ST, OT, PT often provided via school for special education, etc., due to inadequate funding/limited financial resources for additional services (Grewal, 2010). On the other hand, music therapy and adaptive physical education were more frequently used than social skills training. These findings suggests that minoritized groups may prefer to utilize services that are more similar to afterschool or extracurricular activities, rather than social skills training that can be viewed more as directly addressing social challenges associated with autism. It is possible that families' attitudes towards ASD and/or poor understanding of ASD and child's need for targeted services may serve as obstacles to accessing some approaches like social skills training (Rivard et al., 2019).

In terms of findings around association of stigma with service utilization, our findings were in contrast to our hypotheses that higher endorsed stigma would relate to lack of utilization of autism-related services. It is surprising that stigma did not relate to autism-specific services such as ABA, as stigma is well-documented to serve as a barrier to services in ethnic minority groups (Gary, 2005; Montenegro, 2022; Sakai et al., 2019). It is possible that decision around specific treatment approaches may depend more on cost of treatment and lack of parent's availability for other types of services than ABA and auxiliary services like ST and OT, rather than stigma in these groups, given that significant relationships between stigma and service use in frequently-used approaches except in physical therapy. In addition, despite consequences of stigma around autism that significantly contributes to difficulties that families face (Kinnear et al., 2016), families may still choose to access services that are generally available such as ABA, ST, OT, music therapy, and adaptive physical education.

Also, interestingly, higher endorsement of stigma was correlated with the use of PT. It is possible that PT is perceived by the families who endorsed higher level of stigma around autism as "less stigmatizing," and they may be more open with addressing physical aspects rather than other core symptoms of autism (Mitter et al., 2019).

Conclusion

Our findings all tie to the purpose of this study through its overall message that, while stigma may serve as a cultural barrier that limits access to specific approaches, the relationship is more nuanced and may depend on the type of services in consideration. It will be important to continue the examination of factors that could impact autism-related service utilization in ethnoracial minority groups to further reduce the health disparity in these populations. For instance, it will be important to further reduce stigma in families, via various approaches including educational and psychosocial training for the public and professionals, as well as positive messaging around autism in media and public spaces, and cultural and systemic shifts that foster inclusivity and recognize neurodiversity (Turnock et al., 202; Kim et al, 2022). This will bring forth a brighter future for families of autistic people to reduce their experience of stigma as there are more and more people around the world that are starting to gain more acceptance towards those around them.

Limitations

There are several limitations to this study that can be improved upon in future studies. One is that the study had small sample size, especially those in MENA and East African groups. Therefore, a larger sample size of participants in these underrepresented groups could be used and to further examine group differences. Moreover, this study lacked information whether stigma and service utilization related to other factors like service providers, locations (community settings vs. home settings), etc. to see if there are associated effects related to stigma. To extend the study, it may be helpful to examine and account for the perception the target minority groups (South Asians, MENA, East Africans) have towards different types of interventions approaches like physical therapy and social skills trainings.

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