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Differential Diagnosis of Autism Spectrum Disorder: the Impact of Racial and Cultural Diversity
on Caregivers' Perceptions and Reports of Symptoms

Clara Dooley

Faculty Supervisor: Susan Scully-Hill, Ph.D.

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Abstract

Previous studies have produced evidence that a disparity exists in the identification of autism spectrum disorder (ASD) among children of different racial, ethnic, and cultural backgrounds. The findings of these studies suggest that in the United States, having a White, non-marginalized identity can serve as a facilitator to receiving an earlier and more accurate diagnosis, or any diagnosis at all. The present study examined four recent peer-reviewed articles and one dissertation which explore the role of diversity in ASD diagnosis, specifically the ways in which cultural factors may impact caregivers' interpretations and reports of symptoms, and pursuit of services for their child. The goal of this meta analysis was to understand potential reasons why caregivers of diverse backgrounds may respond to the same symptoms differently. Four themes were identified as possible factors which may dissuade those from marginalized identities from reporting symptoms and seeking services. These themes include decreased awareness of ASD, decreased trust in mainstream healthcare, cultural stigma surrounding disability, and varying cultural perceptions of the symptoms. It is necessary for human services workers, educators, and healthcare providers to be keenly aware of the implications of cultural differences on screening for diagnoses and for intervention systems to be accessible and inclusive for all, if this issue is to be remedied.

Introduction

For children with disabilities, receiving an early and accurate diagnosis is critical to maximizing their success later in life. This is the case for physical disabilities and chronic medical conditions, neurodevelopmental disorders such as autism spectrum disorder (ASD), intellectual and learning disabilities, speech/language impairments, behavioral disorders such as oppositional defiant disorder (ODD), conduct disorder (CD), and attention deficit hyperactivity disorder (ADHD), and emotional disorders such as depression and anxiety. The many benefits of a timely official diagnosis include eligibility to receive Early Intervention, Special Education, and countless other services that can be beneficial in optimizing the child's functional development. Evidence shows that receiving these interventions and treatments is associated with "better developmental functioning, fewer maladaptive behaviors, lower symptom severity, improved language and socio-emotional skills, reduced intellectual impairment," and other benefits (Emerson, Morrell & Neece, 2016, p. 127). According to Bailey, Hebbeler, Spiker, Scarborough, Mallik & Nelson (2005), Early Intervention services are effective in both benefiting the child and providing the families with the skills, knowledge, and confidence to care and advocate for their child. However, for many of the aforementioned neurodevelopmental disorders, behavioral disorders, and emotional disorders usually identified in childhood, recent studies have found evidence that symptomatically comparable children sometimes receive differential diagnoses. Specifically, a disparity may exist in the identification of ASD in White and BIPOC (Black, Indigenous, People of Color) children.

ASD is a neurodevelopmental disorder that affects 1 in 54 children in the United States (Centers for Disease Control and Prevention, 2020). ASD is identified using the criteria listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) as well as a variety of other

assessment instruments, and allows for a dimensional rather than categorical diagnosis. Stated differently, it manifests in a variety of ways among individuals and to different extents, however, some defining characteristics tend to be consistent. There are five criteria for the diagnosis of Autism Spectrum Disorder according to the DSM-V, each of which are further broken into more categories. The five main criteria, as delineated in the DSM-V, are as follows: the individual must display persistent deficits in social communication and social interaction across multiple contexts; the individual must display restricted, repetitive patterns of behavior, interests, or activities; symptoms must be present in the early developmental period (but may not fully manifest until social demands exceed limited capacities); symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning; and these impairments are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (American Psychiatric Association, 2013).

ASD is a condition thought to affect all children equally, regardless of demographics. It has no known biomarkers, and there is no evidence that people of specific racial and ethnic groups are more predisposed to this disorder than others. Therefore, the disparity exists within official identification of the disorder, not the presence or absence of the disorder. Diagnosis of ASD relies on professional observation and caregivers' reports of the child's symptoms (APA, 2013). Additionally, one factor associated with an earlier diagnosis of ASD is higher levels of expressed caregivers' concern about initial symptoms (Daniels & Mandell, 2014). However, many daily behaviors are culturally-specific and a universal assessment cannot always be accurately made. Caregivers of different backgrounds may have varying perceptions of disability and of what is seen as typical and atypical (Tincani, Travers & Boutot, 2009); this can potentially be due to the beliefs and traditions of their culture, and also their awareness of ASD symptoms.

Moreover, a lack of cultural competence can create a barrier and prevent understanding between the assessor and the marginalized families.

The purpose of this meta analysis is to explore the existing research regarding caregivers' interpretation and reports of symptoms, and how this may potentially contribute to differential diagnosis of ASD. Previous evidence has highlighted the influence that diverse racial, ethnic, and cultural backgrounds have on the identification of this disorder. Thus, the goal of this study is to further examine cultural factors that may impact, specifically, caregivers' perceptions and responses to their child's developmental or behavioral concerns.

Literature Review

Race, ethnicity, and culture are important features of a person's identity, and impact their daily life. While ethnicity and culture refer to common characteristics of heritage connecting groups of people, the concept of race is a construct associated with physical characteristics (such as skin color) that are believed to make people socially distinct (Desmond & Emirbayer, 2015). Marginalized groups and people of diverse backgrounds face challenges as a result of their race, ethnicity, and/or culture. The intense history of racism in the United States has led to the current presence of institutionalized racism in the nation as a whole and implicit racial bias within individuals. Institutionalized racism is present in many systems in the United States including healthcare, housing, and the criminal justice system, and is characterized by systemic advantages for one racial group at the expense of others. Symbolic power is a component of this and refers to one racial group being classified as the "norm" and others as "deviant" (Desmond & Emirbayer, 2015).

In the United States, Whiteness is the norm and a pertinent example of this is the APA. The DSM-V, developed by the American Psychiatric Association in 2013, is used to classify and diagnose mental disorders. According to the APA, the fifth edition of the DSM incorporates increased cultural sensitivity by reflecting variations in presentation which is meant to help clinicians be aware of relevant contextual information. However, there is very little representation in the APA of BIPOC compared to White people. This suggests that the DSM-V is not universally applicable to all racial, ethnic, and cultural groups, and this may lead to inconsistencies in diagnosis. Furthermore, service providers can still exhibit implicit bias and cultural incompetence when treating individuals of different backgrounds. Implications of this include the subsequent difficulties that marginalized groups may experience accessing the diagnostic and treatment services that they need.

Particularly, children with mental health complications and intellectual and developmental disabilities may receive differential diagnoses as a result of their racial, ethnic, and cultural identity. There is no significant evidence that these factors can independently predispose individuals to certain conditions. Despite this, the Center for Disease Control reports that the prevalence of ASD is lower among Black children than White children (according to 2014 data), suggesting a racial or ethnic component in the disparity in diagnosis of this condition (CDC, 2018). For example, Black children are diagnosed with ASD at overall lower rates than White children (Tincani et al., 2009), and are more likely to be diagnosed with ASD at a later age (Mandell, Wiggins, Carpenter, Daniels, DiGuseppi, Durkin, ... Kirby, 2009). Additionally, Black children are more likely to receive another diagnosis before being diagnosed with ASD (Mandell, Ittenbach, Levy & Pinto-Martin, 2007), and are more likely to be misdiagnosed altogether with certain other conditions (Mandell et al., 2007). There are a variety of proposed

explanations for a missed or delayed ASD diagnosis for children from BIPOC backgrounds which can be separated into four categories based on common themes. The first two themes -- problems with the provider and lack of access -- relate to the bias and institutionalized racism that marginalized groups experience every day in the United States and around the world. The other two themes -- insufficient information and knowledge, and factors relating to specific diverse cultures and corresponding perceptions of disability as a concept -- relate to cultural barriers that can prevent or delay an ASD diagnosis. These final two themes will be explored in much greater detail throughout the rest of this paper.

Multiple studies have cited the service provider's slow response to concerns expressed by caregivers as one factor leading to a missed or later ASD diagnosis (Mandell et al., 2007). This leads to a delayed referral to a psychologist to receive further assessment and diagnosis. Similarly, other studies mention a lack of attention to the caregiver's concerns during primary care appointments along with perceived racism, which caused poor interactions between the caregiver and service provider (Dababnah, Shaia, Campion & Nichols, 2018). This also shows disrespect to the family or caregiver if the providers fail to take their concerns seriously. Additionally, the presence of implicit bias from the practitioners is a cause for a delayed or failed diagnosis of ASD (Morgan & Farkas, 2016). Many healthcare and other service providers possess implicit bias against marginalized groups and they may not even be aware of it. This can impact the quality of services they provide, especially if they do not actively work to combat this internalized bias and pursue growth in cultural competence.

Furthermore, diagnostic and treatment services are not equally available to all members of society. Parikh, Kurzius-Spencer, Mastergeorge & Pettygrove (2018) cite the lack of "community resources... and educational and financial resources" (p. 2397) as cause of a missed

or later ASD diagnosis for BIPOC children and families. Marginalized and underprivileged groups are given decreased access to resources that would benefit them in every area of life, including healthcare. Institutionalized racism disadvantages BIPOC and can hinder them from accessing the services necessary to maximize growth and functioning when faced with a disability. Limited healthcare access is also a likely factor of missed or delayed ASD diagnosis (Morgan & Farkas, 2016), because a family that does not have a consistent source of medical care will face a barrier to receiving the necessary services for the diagnosis and services of ASD (Emerson et al., 2016).

Another potential barrier to diagnosis is the families' lack of awareness of the symptoms of ASD (Mandell et al., 2007; Morgan & Farkas, 2016). Being poorly informed about the condition might inhibit caregivers from recognizing the signs and thus seeking further services for the child. Paired with the lack of attention or concern from the provider, even when the caregiver does recognize the signs, this can delay the diagnosis further or prevent it from being made at all.

Lastly, a final theme noted from the literature addresses differences in the ways that various diverse cultures may view and treat disabilities and specific behaviors. This can certainly impact the diagnostic process. Most of the ASD diagnostic measures are based in an extremely White and Westernized viewpoint, and fail to consider diversity and culture as factors. Ratto, Anthony, Kenworthy, Armour, Dudley & Anthony (2016) suggest that different "cultural expectations of socially appropriate behavior, [and] parental knowledge and beliefs about development" (p. 773) may impact differential diagnosis and seeking services. Diagnostic measures often fail to take into account the possibility that cultural and linguistic differences may affect assessment outcomes, or the pursuit of assessment in the first place (Tincani et al., 2009).

These differences can lead to differential results of standardized testing, particularly caregiver-report scales (Ratto et al., 2016, p. 773). For example, Harrison, Long, Tommet & Jones (2017) report that item level biases exist in the Autism Diagnostic Observation Schedule (ADOS) which can cause cultural factors to sway the results. One major hallmark of ASD is “social deficits,” however, there are differences in social norms across cultures. Some of these cultural differences include eye contact, facial expressions and recognition, language, play, and behavioral interactions (Harrison et al., 2017). Therefore, caregivers may report differently on certain symptoms because they do not view them as abnormal or concerning. Moreover, Tincani et al. (2009) report that culture can impact the way that a caregiver interprets the presence of disability in their child. It also affects beliefs about the goals that should be made for their children to achieve through interventions. Mandell & Novak (2005) assert that caregivers’ perceptions of their child’s symptoms as typical or atypical, problematic or unproblematic, and wilful or disabling, may vary by culture. This view will also affect whether they seek services for their child (and what kind), which can have a drastic impact on long term outcomes.

Methodology

The original purpose of this study was to investigate the degree to which differential diagnosis plays a role in the local Worcester Public Schools (WPS) system. Worcester, Massachusetts is the second largest city in New England and has a population of approximately 185,400. About 69.2% of the population is White, and about 13.3% of the population is Black (United States Census Bureau, 2019). This is fairly reflective of the nationwide percentages in racial demographics. The inquiry focused on examining the intersectionality of race, ethnicity, and culture with the diagnosis and services for various childhood disabilities. Specifically, the

research questions were: 1. What are the extent and implications of the differential diagnosis of disabilities (among racial/ethnic groups) as perceived by educational professionals in WPS? and, 2. What is the extent to which education and resources relating to diversity and cultural competence are provided to educational professionals in WPS? A survey research methodology was to be employed in an attempt to answer these research questions, and administered to participants taken from a convenience sample of WPS professionals, including school psychologists, adjustment counselors, and special educators.

The survey draft (see Appendix A) was designed to elicit the perspectives of these educational professionals on the differential disability diagnoses of White and BIPOC children in the school setting. Survey items were developed by reviewing the existing literature, specifically studies which were conducted with a similar purpose and research questions. The survey was created knowing that there would have been revisions upon pilot testing. It was hoped that some of the survey participants would be willing to partake in a brief interview to gather more information on their perspectives.

However, the onset of the COVID-19 pandemic resulted in the removal of students and staff from schools. The switch to remote and hybrid learning proved to be a challenge for public school professionals as they adapted to the new way of teaching and providing services to students. As a result, identifying participants to partake in this study was not feasible within the time constraints available to collect data.

Therefore, a type of meta analysis was pursued. The focus of the research shifted from the professional perceptions of the differential diagnosis of disabilities in public schools to cultural influences on caregivers' perceptions and reports of ASD signs. Given that marginalized families tend to be slower to receive an ASD diagnosis for their child, this study seeks to

understand the extent to which this can be attributed to the caregivers' reports. The present research questions are 1. Does cultural diversity impact a family's interpretations and responses to the signs of ASD in their child? and if so, 2. Why are caregivers who are members of marginalized groups less likely to report concerns about their child's development? This meta analysis will review the existing literature about the effects of race, ethnicity, and cultural background on caregivers' reports of their child's symptoms and the role that this may ultimately play in differential diagnosis of ASD. Four peer-reviewed studies and one dissertation have been selected for review and analyzed for common themes.

Results

The following studies were selected for review because of their relevance to the issue of racial, ethnic, and cultural disparities in the identification of ASD. These studies examine the racial and cultural backgrounds of caregivers and families, and how these may serve as barriers or facilitators to their child's diagnosis. Particularly, the difference in caregivers' reports of symptoms on the basis of race, ethnicity, and culture will be explored as a potential contributor to differential diagnosis. Each study offers valuable information and several common themes can be found throughout. All of the studies are based on the acceptance of differential diagnosis of ASD, and presuppose that there are racial, ethnic, or cultural differences in the ways that different families view disabilities which can contribute to the differential diagnosis. They are presented in alphabetical order by author.

Study 1

_____Dababnah, Shaia, Campion & Nichols (2018) completed a qualitative study titled "We Had to Keep Pushing: Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care." This research solicited information on the first hand

experiences of Black children with ASD and their caregivers. This study was carried out in light of previous evidence that Black children with ASD are more likely to be diagnosed later than White children with ASD, and are more likely to be diagnosed inaccurately. The researchers sought to identify the potential causes for this. This research was also grounded in the Public Health Critical Race Framework (PHCRF), which asserts that race does not inherently predispose people to certain health outcomes, rather, it cites structural racism in the external environment as the cause of health related disparities among racial groups. As stated previously, there is no evidence of a biological basis for ASD diagnosis, rather, “enabling factors include community-specific cultural factors that can influence timely ASD diagnosis” (Dababnah et al., 2018, p. 323). Therefore, the purpose of this study was to identify various barriers and facilitators to obtaining an ASD diagnosis experienced by the caregivers of Black children in primary care settings.

This research took place by conducting personal semi-structured interviews with 22 Black female caregivers of Black children with ASD, living in Baltimore, Maryland. Their perspectives and personal experiences regarding their child’s diagnostic process were solicited. Their responses revealed common challenges faced by the participants, and various factors which they believe may have contributed to a delayed or inaccurate diagnosis.

Outcomes

Four major themes emerged from the interviews. First, many of the participants discussed the responses of their primary healthcare providers to their concerns. While some reported that their providers paid close attention to their needs, many described a long journey of directly seeking intervention services and persistence in asking for referrals. This occurred because their healthcare providers tended to either dismiss their concerns or remain unwilling to provide a

referral. As a result, many of the caregivers were forced to identify the signals of ASD on their own and pursue diagnostic and therapeutic resources without the help of their provider.

The second theme that arose was that of perceived racism and poor caregiver-provider interactions. Many of the Black caregivers reported feeling uneasy in interactions, and tended to attribute it to implicit bias. The vast majority of service providers were White, and as a result, the families reported feeling disconnected from and misunderstood by them. Some also recounted instances in which they felt that negative assumptions were made about them or their families on the basis of their race, such as the assumptions that they were not employed, married, or well educated.

The third theme that came to light in these interviews was the stigma surrounding ASD within the Black community. Several participants cited the high levels of shame and denial within their racial group related to having a child with special needs, and said that this perception of ASD was a source of discomfort for them. They revealed that the influence of shame and denial results in decreased awareness of the condition. In addition, this can lead to hesitation to seek diagnostic services out of fear of judgement from family and other members of the community.

Finally, the fourth theme pertains to legal and custodial issues around caregiving arrangements. Unlike the other themes, this is not specific to the Black community, although it was an issue that affected many of the families in this study. Changes in caregiving arrangements created an obstacle to achieving an ASD diagnosis for several of the families.

Study 2

Donohue, Childs, Richards & Robins (2019) completed a research study entitled “Race Influences Parent Report of Concerns About Symptoms of Autism Spectrum Disorder.” This

study sought to identify potential differences in the concerns voiced by caregivers of varying races regarding their child's development. It is believed that when reporting, caregivers of different backgrounds may tend to emphasize certain symptoms depending on the cultural importance of that skill. Therefore, the goal was to find trends in caregivers' reports of concerns correlating with the racial identity of the child and caregiver. The researchers hypothesized that before obtaining an official ASD diagnosis, White parents report more ASD symptom-specific concerns and that Black parents report more concerns about disruptive behaviors, as compared to each other. Stated simply, this study focused on the ways in which Black and White caregivers (of children who would eventually be diagnosed with ASD) reported their concerns pertaining to their child's development.

The participants of this study were 174 toddlers between the ages of 18 and 40 months old and their caregivers. The original sample size was greater, but only the data from those children who were actually diagnosed with ASD during the evaluation are included in the final report. 60.9% of the children and 66.7% of the caregivers were White, and 39.1% of the children and 33.3% of the caregivers were Black. The data were gathered after each child was screened and declared to be at risk of ASD, but before undergoing a diagnostic evaluation. Therefore, the caregivers' responses were not influenced by the knowledge that their child did or did not have ASD. To test the hypothesis, caregivers were asked three questions: "Please briefly list any concerns/worries you have about how the child has been developing (walking, speaking, playing) or behaving," "Concerns about your child's development," and "What were the first things that made you concerned about your child's development?" (Donohue et al., 2019, p. 103).

The responses to these questions were divided into concern categories which were labeled as either the ASD concern category or the non-ASD concern category. The former

contained concerns which were reflective of ASD diagnostic criteria, consisting of concerns related to speech/communication, restrictive/repetitive behaviors (RRB), social impairments, and the direct mention of ASD by the caregiver (ASD label concern). The latter contained concerns that did not necessarily point to ASD, including those relating to motor difficulties, behavior/temperament, medical conditions, general developmental concerns, feeding, and disruptive behavior. The study was split between two locations, one in Connecticut and one in Atlanta, Georgia. Once the caregivers had answered the questions and participated in the study, the children were evaluated for ASD by a licensed clinician using a variety of assessment measures.

Outcomes

Across the ten individual concern categories (four ASD concern categories and six non-ASD concern categories), White caregivers reported more concerns about their child's development than Black caregivers. Overall, concerns about speech and communication were the most prevalent, followed by concerns about motor and social development for both groups. As hypothesized, significantly fewer ASD symptom-specific concerns were expressed by Black parents than White parents. More specifically, White parents were 2.61 times more likely to report social concerns and 4.12 times more likely to report RRB concerns than Black parents. However, there was no significant difference between racial groups in the concerns reported within the non-ASD category. Furthermore, race did not significantly impact the parents' reports of speech/communication concerns, ASD label concerns, or disruptive behavior concerns.

Study 3

Issarraras, Matson, Matheis & Burns (2019) performed a research study called "Differences in Developmental Concerns of Young Children with Autism Spectrum Disorder

Across Racial/Ethnic Groups.” The researchers cited previous studies which suggest that there is not a significant relationship between racial/ethnic identity and the age of the child when the caregiver first expresses a concern. Therefore, this research sought to discern whether specific types of initial concerns pertaining to development were more or less likely to be reported by caregivers of diverse backgrounds. The researchers hypothesized that the types of initial developmental concerns expressed by caregivers vary across racial groups.

The participants of this study were 1,205 children (13-39 months old) meeting ASD diagnostic criteria according to the DSM-V, and their caregivers. 45.6% of participants were Black, 45.1% were White, and 3.8% were Hispanic. These children were all enrolled in a statewide early intervention program in Louisiana and therefore had already received an official diagnosis. The instrument used to gather caregivers’ concerns about their children was the Baby and Infant Screen for Children with aUtism Traits, Part 1 (BISCUIT-1). This is an informant-report measure that therefore provides insight to caregivers’ perspectives and interpretations of their child’s symptoms. This assessment includes 62 items and the caregiver is asked to rate each item on a scale of 0-2 depending on how greatly their child differs from same aged peers in that particular area. Categories of developmental concerns include general/overall, communication, motor, problem behavior, social, feeding, sensory, weight, prematurity, attention, adaptive functioning, and medical concerns.

Outcomes

There were no significant differences in the average age of first developmental concern across racial groups. White caregivers tended to endorse higher frequencies of concerns in nearly all concern categories, however, the frequencies were fairly comparable in many of them. There were no significant differences in the frequency of report of initial concerns related to

communication, motor, problem behavior, feeding, sensory, weight, prematurity, attention, adaptive functioning, and medical. Across all groups, the most commonly reported initial concerns were related to communication. The most significant difference between racial groups was found in the endorsement of social concerns. White caregivers were significantly more likely to report a concern in the social development of their child than Black or Hispanic caregivers. In fact, more White caregivers and fewer Black and Hispanic caregivers expressed social concerns that would be expected.

Study 4

_____Johnson (2014) completed a dissertation entitled “Autism Spectrum Disorder: the Role of Ethnicity and Culture in Parent Interpretation and Service Utilization.” The purpose of this study was to identify the influence of race and culture on caregivers’ perceptions of disability prior to service utilization. The researcher looked at the caregivers’ conceptualizations of ASD symptoms, approaches to seeking services when needed, and general stigma regarding mental health and disabilities. Specifically, the measures administered to the caregivers were intended to understand their perspectives on problem identification and need for intervention, knowledge of ASD, and attitudes towards healthcare providers and seeking mental health services (Johnson, 2014). The participants of this study were 119 female caregivers, each with at least one child between the ages of roughly two and ten. The children of the participants were typically developing and not known to be at risk of ASD or any other diagnosis. The participants were all living in northern Mississippi and 51.3% were Black and 48.7% were White.

To assess the caregivers’ interpretations of symptoms, each participant was shown a series of three vignettes depicting a child with typical development, a child with mild ASD symptoms, and a child with more severe ASD symptoms (Johnson, 2014). The participants were

then asked a series of 7 questions about their levels of concern for the child, their opinions about what is affecting him, and what they would do if they were his caregiver. The goal of this was to explore the caregivers' interpretations of ASD symptoms and the type of help that the caregiver would pursue. Caregivers' attitudes towards help seeking were assessed using the Parental Attitudes Toward Psychological Services Inventory (PATPSI). This instrument included 21 statements related to seeking professional help which were to be ranked on a 6-point scale from "strongly disagree" to "strongly agree." Additionally, the Group Based Medical Mistrust Scale (GBMMS) was used to assess the individuals' beliefs pertaining to the competence of "mainstream healthcare systems and medical professionals to provide treatment to people in their ethnic/racial group" (Johnson, 2014). This assessment included 12 statements related to medical trust which were also to be ranked on a 6-point scale from "strongly disagree" to "strongly agree." Finally, to measure the participants' knowledge of ASD, a questionnaire was administered which contained 14 true/false questions about ASD.

Outcomes

In the first measure, White caregivers were more likely than Black caregivers to correctly identify the child in the vignette as having a developmental disorder such as ASD rather than something else. However, the two groups of caregivers did not differ significantly in their ability to identify that there was something affecting the hypothetical child's development. Next, the results of the PATPSI and GBMMS indicate that Black caregivers reported higher levels of suspicion regarding medical treatment and services for disabilities than White caregivers. They also reported higher levels of the belief that racial and ethnic disparities exist in the quality of medical treatment received. The results of the ASD knowledge questionnaire reveal that White caregivers possess increased knowledge about ASD compared to Black caregivers. However, on

Item 1 of this questionnaire, there was no significant difference in the caregivers' agreement that early intervention can positively impact the social and communication skills of children with ASD.

Study 5

Ratto, Anthony, Kenworthy, Armour, Dudley & Anthony (2016) conducted a research study entitled "Are Non-Intellectually Disabled Black Youth with ASD Less Impaired on Parent Report than Their White Peers?" The researchers sought to examine caregiver-reported levels of impairment in daily functioning for Black children compared to White children diagnosed with ASD. Daily functioning was broken into three subgroups: executive functioning, adaptive behavior, and social/emotional functioning. The purpose of the study was to compare the ways in which Black and White caregivers of children with ASD perceive and report on their child's symptoms, and then to investigate how this may impact the child in the long term. The researchers hypothesized that based on caregivers' reports, Black participants would have greater impairments than White participants in executive function, adaptive behavior, and social/emotional functioning.

The participants of this study were 64 children between the ages of 6 and 17. All of the children had been officially diagnosed with ASD but did not possess an intellectual disability. Half of the participants were Black and half were White. Each Black participant was paired with a White participant of comparable age, gender, IQ, and socioeconomic status. The participants' cognitive abilities were measured using the Wechsler Abbreviated Scale of Intelligence (WASI) to assist in the pairing process. The participants were then assessed on executive functioning, adaptive behavior, and social/emotional functioning using caregiver-report assessment instruments. Executive function abilities were assessed using the caregiver form of the Behavior

Rating Inventory of Executive Function (BRIEF). This questionnaire required the parent or caregiver of each child to report on their “ability to inhibit, shift and modulate behaviors and emotions appropriately” (Ratto et al., 2016, p. 776) and their “ability to cognitively plan, organize, and manage information and tasks and monitor performance” (Ratto et al., 2016, p. 776). Assessment of adaptive behavior occurred using the Vineland Adaptive Behavior Scales, Second Edition (Vineland-II). The researchers utilized a Survey Interview format to gather information from the parents and caregivers about the child’s communication skills, daily living skills, and social skills. Finally, social/emotional and behavioral functioning was assessed using the Child Behavior Checklist (CBCL). This questionnaire is administered to parents and caregivers and seeks to identify both internalizing and externalizing symptoms of psychological disorders.

Outcomes

The results of this study show that Black caregivers reported their children to be less impaired in executive function, adaptive behavior, and social/emotional functioning compared to White caregivers, even when the children were symptomatically equivalent. Black participants had significantly lower scores on the BRIEF and CBCL, which indicates that the caregivers reported lower levels of impairment in executive functioning and social/emotional functioning, and higher scores on the Vineland-II, which indicates that the caregivers reported better adaptive functioning. Across all measures, Black childrens’ mean scores fell in the non-clinical range on all scales, while of the White childrens’ mean scores fell in the clinically-impaired range on most scales.

Conclusion

This meta analysis sought to answer the following research questions: 1. Does cultural diversity impact a family's interpretations and responses to the signs of ASD in their child? and if so, 2. Why are caregivers who are members of marginalized groups less likely to report concerns about their child's development? All five of the selected studies contributed to answering these research questions and each approached the overall common topic in a unique way. Study 1 stands out because rather than simply collecting data on the caregivers' reports of their child's symptoms, the researchers actually asked the caregivers about their personal and cultural perspectives and viewpoints regarding the diagnosis of ASD, and why they believe that diagnosis may occur differently among groups of people. This information can potentially be used to explain differences in caregiver reports on the basis of race, ethnicity, and culture. Study 2 and Study 3 examined the differing tendencies of Black and White parents to report on certain specific concerns about their child's development. Study 4 looked for differences in Black and White caregivers' conceptualization of ASD symptoms, knowledge of ASD, attitudes towards seeking professional help for conditions, and biases towards mainstream healthcare. Finally, Study 5 investigated differences in Black and White caregiver reported levels of impairment in executive functioning, adaptive behavior, and social/emotional functioning for their children with ASD.

The studies are all based on the acceptance that caregivers' expressions of concerns and advocacy for their child play a monumental role in gaining a diagnosis. Caregivers who report concerns about their child's development to their healthcare provider are more likely to receive a referral for an evaluation for their child than caregivers who do not voice concerns. Each study sought to gather information about differences in caregivers' reports across racial and ethnic

groups. The results of these studies suggest that some disparity exists between Black and White caregivers' reports of concerns about their child's development. Based on the sum of these findings, White caregivers tended to report more concerns overall and were more likely to express concerns specifically related to ASD. Black caregivers reported lower levels of impairment in their child's functioning, and higher levels of suspicion towards medical and psychological healthcare services.

It is probable that these differences may contribute to the lower rates of diagnosis, the likelihood of receiving a delayed diagnosis, and the risk of misdiagnosis experienced by BIPOC children compared to White children. There are many potential explanations for why caregivers of diverse backgrounds may interpret and report on the same symptoms differently, and four common themes pertaining to this were identified throughout the five studies. Caregivers are less likely to report on their child's symptoms if they have decreased awareness and knowledge of the symptoms of ASD, if they have decreased trust in the healthcare system, if they face stigma in their communities regarding disability and are adverse to labels such as "autism," and if they have different cultural perceptions and interpretations of the symptoms. Moreover, many of the caregivers who happen to fall into one or more of the aforementioned categories are members of diverse or marginalized racial, ethnic, and cultural groups.

There is some noticeable overlap between these themes and the previously discussed themes derived from the literature which may explain the causes of a missed or delayed ASD diagnosis for BIPOC children: problems with the provider, lack of access, insufficient information and knowledge, and factors relating to specific diverse cultures. These overlaps are indicative of the connection between caregivers' reports of signs and differential diagnosis of

ASD. Some of these themes impact differential diagnosis directly, and some impact caregivers' reports which in turn may impact differential diagnosis.

Theme One: Awareness of ASD Symptoms

Caregivers are less likely to report concerns if they have decreased awareness of ASD. This may lead caregivers to be less likely to recognize the signs and bring their concerns to their provider. Several of the studies indicate that White caregivers tend to have more knowledge of the signs of ASD than Black caregivers.

In Study 2, White caregivers not only expressed more concerns overall, but were also more likely than Black caregivers to express concerns that are indicative of ASD specifically. White caregivers were more likely to report concerns within the ASD concern category, including concerns relating to social development and RRB (Donohue et al., 2019). The authors of Study 2 explain that some Black caregivers of children with ASD admit to believing that they have less awareness and access to resources about ASD than White caregivers (Donohue et al., 2019). This is in agreement with previous research which indicates that disadvantaged groups will face decreased access to education and services that will be beneficial in all areas of life.

The author of Study 4 reported that White caregivers were more likely than Black caregivers to identify the child in the vignettes as having ASD specifically, as opposed to something else. Additionally, the results of the autism knowledge scale reveal that the White parents had higher levels of knowledge about ASD than Black caregivers (Johnson, 2014). Some Black caregivers in Study 4 reported that they had less information and familiarity regarding ASD, and that it was not commonly addressed in their communities (Johnson, 2014). This may contribute to delays in seeking diagnosis and treatment.

Some of the participants in Study 1 explained that their providers did not take their concerns seriously, so they were forced to persistently ask for referrals and independently seek services. Without knowledge of the condition and awareness of the necessary next steps, it is difficult for caregivers to advocate for the needs of their child. Therefore, the lessened awareness of ASD experienced by some BIPOC and members of marginalized groups may serve as a barrier to reporting concerns about their child's development.

Theme Two: Mistrust in Mainstream Healthcare

Even when caregivers do recognize the signs of ASD or have concerns about their child's development, they may hesitate to report on these things honestly if they have diminished trust in mainstream healthcare systems and individual providers.

The first two themes drawn from Study 1 relate to the implicit bias of the healthcare providers and otherwise unpleasant and unsuccessful interactions between the Black caregivers and their child's healthcare providers (Dababnah et al., 2018). Poor experiences with the healthcare system will cause BIPOC to be less likely to trust them and seek help from them in the future. This bias and lack of confidence in mainstream healthcare may serve as a barrier to reporting concerns. The authors of Study 2 report that previous research has indicated that decreased help-seeking tendencies exist among Black individuals (Donohue et al., 2019) due to this mistrust which can certainly delay or inhibit an official diagnosis from being made.

In Study 4, the author explains that Black caregivers tend to seek services later and less frequently than White caregivers, and this may be due (at least in part) to negative experiences with healthcare in the past, often relating to provider bias (Johnson, 2014). The results of this study revealed that Black participants reported higher levels of medical suspicion and tended to be more likely to believe that medical treatment is provided unequally to people of different

racial backgrounds. This may be explained by the results of another assessment in this study which shows that Black participants were more likely than White participants to agree that they had personally experienced unfair treatment from a healthcare worker as a consequence of their race (Johnson, 2014). These data align with the commonly accepted fact that people of privilege in the United States, particularly White people, have access to better medical services and are treated better by the healthcare system than disadvantaged groups of people.

Theme Three: Stigma Within Communities

Caregivers will also be less likely to report on symptoms, especially symptoms of ASD, if they experience stigma around the topic of disabilities in their communities or do not want their child to be labelled with a diagnosis.

The third theme from Study 1 discusses this barrier that is faced by some Black caregivers. Several of the participating caregivers cited stigma within the Black community surrounding disability as a barrier to seeking and receiving diagnostic and treatment services. They explained that in their cultural experience, a degree of denial and shame is associated with having a child with a disability or with special needs (Dababnah et al., 2018). Additionally, these sentiments can accompany resistance to the diagnosis of ASD as a label to one's child. Several participants also mentioned that other members of their families were not comfortable with the ASD label and worried that they would be judged. It is probable that this lack of community support around raising a child with a disability is at least partially rooted in the decreased awareness of ASD that was discussed previously. Furthermore, this stigma could certainly delay or impair the process of seeking and obtaining services for a child with ASD symptoms.

Moreover, multiple types of stigma can affect caregivers' reports of concerns relating to their child's development. Caregivers will be less willing to seek help if they face stigma from

family, friends, and other members of their community. Additionally, they will be less willing to seek help if they have stigma towards healthcare providers, or believe that the healthcare system is biased against them because of their racial or ethnic identity.

Theme Four: Cultural Perceptions of Disability

Finally, caregivers may be less likely to report concerns about the signs of ASD if they view the signs differently as a result of their culture. Diverse cultures may have different expectations or interpretations of behavior and development.

The authors of Study 2 suggest that caregivers of different cultural backgrounds may perceive certain symptoms as more or less concerning or problematic, or have different opinions about the level of concern which warrants a report. This will inevitably impact their reports of these symptoms and pursuit of services. The results of this study show that Black caregivers were less likely to report on ASD-specific concerns such as RRB and social deficits, but that they may be more likely to report on other behavior-related concerns (Donohue et al., 2019). Because White caregivers tend to make reports that are more conducive to an ASD diagnosis, this can lead to the higher number of White children diagnosed with ASD. On the contrary, it is likely that this contributes to Black children being more commonly diagnosed with disorders such as ADHD, CD, and ODD. Caregivers may have differing tendencies to emphasize specific concerns depending on the importance of that particular skill within the culture.

Study 3 suggests that racial differences in the types of initial concerns regarding a child's development "may be culturally bound to parents or caregivers' perceptions of their child's development" (Issarraras et al., 2019, p. 175). Perhaps certain skills such as "social skills," as defined by traditional assessment instruments, may be more relevant in White families than in families of other backgrounds which could contribute to the higher levels of concerns.

Similarly, the authors of Study 5 suggest that Black childrens' symptoms may be more often conceptualized as simply behavioral problems than something more. Additionally, cultures may view delays in certain areas to be more concerning than delays in other areas, and this may not line up with the diagnostic criteria set forth in ASD assessment instruments. Cultural differences in "norms," or what is viewed as typical or atypical behavior can also impact caregiver perception and report of symptoms. According to Ratto et al. (2016), caregivers "may observe these behaviors, but perhaps not see them as problematic" (p. 779). Therefore, certain assessment instruments and questionnaires may be less applicable to Black families.

Additional Findings

Although not related to a research question, but an interesting finding nonetheless, Study 1 showed that the average age of each child at the time of the caregivers' first developmental concern was 23.6 months and the average age of each child at the time of ASD diagnosis was 46.3 months (Dababnah et al., 2018). This indicates that the participants of this study did, in fact, express concerns about their children's development, and a delay in diagnosis was likely not attributed to delay in caregivers' reports. For the Black participants in Study 3, the average age at the time of the caregivers' first concern was 14.09 months, and the average age of each child at the time of assessment was 26.18 months. For White participants, on the other hand, the average age at the time of the caregivers' first concern was 13.94 months, and the average age of each child at the time of assessment was 25.76 months (Issarraras et al., 2019). While these data do indicate that the White caregivers expressed concerns and their children were evaluated at a slightly earlier age, the difference is not statistically significant. The other studies do not contain information regarding the ages of the children when they received their diagnosis and when their caregivers first expressed concerns about their development. Therefore, these five studies do not,

in fact, suggest that BIPOC caregivers actually tend to report concerns about their child's development later than White caregivers.

Another interesting finding was derived from Study 2 and Study 3. Both of these studies focused on searching for differences in specific types of concerns expressed by White and Black caregivers. As described previously, there may be variations in the cultural importance of different skill areas which may cause diverse groups of caregivers to emphasize some concerns more than others. However, across all racial groups in both studies, the most commonly reported concerns were those relating to the development of communication skills. Furthermore, in both studies, the greatest disparity existed in the report of social concerns. White caregivers were significantly more likely to report concerns relating to social development than Black caregivers (Donohue et al., 2019; Issarraras et al., 2019). Communication and social deficits both fall into the "ASD concerns" category of Study 2 (Donohue et al., 2019) and are required criteria for the diagnosis of ASD. This disparity suggests a potential difference in the ways that socialization and social deficits are perceived across cultures. Moreover, it is interesting that both groups of caregivers are likely to report concerns in communication skills, but White caregivers are more likely to report concerns in social skills than Black caregivers. It is possible that this is a contributor to the higher rates of ASD diagnosis among White children than Black children.

Discussion

Caregivers' expression of concerns and communication with the provider about these concerns is an essential part of the ASD assessment process. It is often what initiates the process in the first place, and caregivers' reports are used throughout the entire assessment process (Issarraras et al., 2019). The findings of this research are meaningful because they suggest that

cultural differences play a complex role in caregivers' interpretations and reports of concerns about their child's development, which may in turn contribute to the phenomenon of differential diagnosis of ASD. Although more recent data has revealed that the racial gap in diagnosis has been reduced in recent years, the problem of a disparity still exists (CDC, 2020). This neurodevelopmental disorder is identified and studied from a largely White and Westernized viewpoint, and in many ways, the criteria are not universal and inclusive of all groups of people. Diverse cultural beliefs and values can inhibit certain groups of children from receiving a diagnosis, or cause them to be given an inaccurate diagnosis based on the attribution of characteristics to pathology rather than cultural norms. Therefore, research such as this can shed light on this reality and prompt human services professionals to pursue greater awareness of diverse cultures and how this may inform their work and practices.

Although this research has revealed interesting findings, it is limited in that it only examined a small selection of research studies. Other studies on this topic may exist and it is possible that other research may have yielded different results. In addition, the sample sizes within some of the studies were small, and the participants were gathered from only a chosen area. Therefore, results of these studies may not be generalizable to all areas. Most of the studies only included Black and White participants, and thus did not gather data on the experiences and perceptions of people from other racial and cultural backgrounds. Furthermore, these studies gathered information from caregivers who did report on their concerns of their child, and whose children had received an official diagnosis. Thus, these studies exclude caregivers and families who never reported concerns or whose children remain undiagnosed. Though these people are very difficult or impossible to identify for the purpose of research, it is likely that their involvement would alter the outcome of some studies.

Extensive future research is needed to further understand the implications of different specific cultures on the perception of disability, specifically, ASD. Interviews with members of diverse groups would be beneficial in understanding these factors and how they may contribute to the differential diagnosis of ASD on the basis of race, ethnicity, and culture, and what can be done to be more inclusive and culturally competent. It would be interesting to examine individual signs and ASD diagnostic criteria from the perspectives of various diverse cultures. In addition, it would be helpful to perform research on how specific cultures and traditions may view ASD or disability in general. Both of these paths of study would provide compelling insight both separately, and when combined.

It is important that BIPOC caregivers should not be blamed or judged for the ways that differential diagnosis may affect their children. Society and the systems in place were developed to benefit and serve White people, and exist to cater to their way of living. This needs to be amended such that diverse people do not have to conform or change their culture or work significantly harder in order to receive the same treatment and access as White people. These societal changes can begin at individual and community levels. The first two barriers to reporting faced by caregivers stem from external and societal sources. Lack of awareness can be combated by outreach to communities to educate and screen for ASD. The second barrier, mistrust in mainstream healthcare, can only be overcome if healthcare workers and other service providers seek resources to increase their cultural competence so that they can better serve members of marginalized groups. Workers in these fields could be required to study a foreign language beyond the common requirements, to enhance their ability to serve diverse groups. The last two barriers to reporting, stigma within communities and differing cultural perceptions of disability, stem from within the cultural or ethnic group. Instead of trying to fix these factors from the

outside, it would be more beneficial, as a society, to gain an overall increased understanding of different cultures. Differences should be celebrated and all groups of people should be treated equally. Additionally, diagnostic materials should be revised while keeping in mind that they must be made to diagnose members of all backgrounds. After all this, societal changes need to be made to reframe structures such that BIPOC are uplifted and racial inequalities are diminished.

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Appendix A

Survey Instrument

Please complete the following questions about yourself.

1. Race/Ethnic Identity:

- Black or African-American
- Hispanic or Latino/a
- White
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaskan Native

2. Job Title:

- School Psychologist
- Special Education Teacher
- Adjustment Counselor
- Paraprofessional
- Other (please specify) _____

3. School Type:

- Elementary School
- Middle School
- High School
- Other (please specify) _____

4. Town/City of Employment: _____

Please complete the following agree/disagree statements.

5. I am confident in accepting the accuracy of the diagnoses of my White students.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. I am confident in accepting the accuracy of the diagnoses of my BIPOC students.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. I believe that there are students at my school who should receive a certain diagnosis but have not.

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. I believe that there is a trend or disparity in racial/ethnic identity present between the students who have received an appropriate diagnosis and the students whom I believe should receive a certain diagnosis but have not.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Please answer the following yes/no questions and feel free to elaborate in as much detail as you feel comfortable.

9. In your career, have you received training in cultural competence?

- | | Yes | No | Unsure |
|--|-----|----|--------|
| 10. Was this training given through your current job? | | | |
| | Yes | No | Unsure |
| 11. Do you feel that it was a thorough and prioritized training? | | | |
| | Yes | No | Unsure |
| 12. Do you feel that the content of the training is relevant and applicable to your job? | | | |
| | Yes | No | Unsure |
| 13. In your career, have you noticed any racial/ethnic trends in the diagnoses or ages of diagnosis for children with disabilities? | | | |
| | Yes | No | Unsure |

14. Would you say that your observations have aligned with the results of previous studies laid out in the pre-survey sheet?

Yes	No	Unsure
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Please answer the following questions about your willingness to participate in further research.

15. Would you be willing to participate in a brief interview to elaborate on your answers to the survey questions? If you choose yes, you will be contacted to set up a time to talk over Zoom or telephone and further discuss this topic. It will take about 10-15 minutes. Your identity will remain confidential in the final research.

Yes	No
-----	----

16. If yes:

Name: _____

Email: _____

Phone: _____

Name of School: _____

Interview Questions:

- 1. What is your perception of the cause of differential diagnosis?**
- 2. What role does implicit racial bias play in the differences that are discussed in the literature?**
- 3. Have you had any out-standing experiences or interactions with students/families in your career in which you felt that race/ethnicity was a strong factor? Please describe.**
- 4. What do you think can be done to reduce disparities on diagnosis?**