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Examining unconscious bias embedded in provider language regarding children with autism

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Abstract

In healthcare settings, language used by healthcare providers can influence provider–patient encounters with individuals with autism spectrum disorder, impacting feelings of stigma and marginalization. This study highlights the unconscious biases healthcare providers might have regarding their patients with autism spectrum disorder and how those beliefs are articulated. Seven pediatric dentists participated in two focus groups to describe strategies to improve oral care for children with autism spectrum disorder. While completing the primary analyses, additional codes emerged related to healthcare provider biases; these data are the focus of this study. Three themes were identified: (i) “healthcare microaggressions” describe how healthcare providers portray their patients in subtly negative ways; (ii) “marginalization” denotes the use of exclusionary language identifying children with autism spectrum disorder as different; and (iii) “preconceptions” include comments that highlight biases about patients. The findings provide insight into the implicit biases that might be held by healthcare providers and how they manifest in language. Despite increased emphasis on cultural competency, healthcare providers might unconsciously use language that could negatively impact patient–provider rapport and increase stigma in already marginalized populations. Further research is necessary to explore how these biases could relate to quality of care.

Keywords

autism spectrum disorder; bias; children; healthcare provider; stigma

1 | INTRODUCTION

Children with autism spectrum disorders (cASD) and their families experience challenges in healthcare settings and often describe feeling stigmatized (Farrugia, 2009; Kinnear, Link, Ballan, & Fischbach, 2016; Pearson & Meadan 2018). Healthcare providers (HCP) have

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direct contact with this population, primarily relying on communication to build relationships and develop rapport. The language used by HCP can influence provider–patient encounters, impact the stigma associated with a disability, and change the way cASD and their families experience health care. It is imperative that providers be mindful of unconscious bias and utilize self-reflection in consideration of the language they use to describe the populations they serve. Therefore, the purpose of this study was to highlight the unconscious biases that might be held by HCP toward their clients with ASD and explore how those beliefs are expressed in their language.

1.1 | Literature review

ASD is a developmental disability characterized by a series of restricted and repetitive behaviors, social interaction difficulties, and impaired communication (American Psychiatric Association, 2013). According to the Centers for Disease Control and Prevention (2018), there is a 1–2% average prevalence of ASD in Asia, Europe, and North America, with reports among all racial, ethnic, and socioeconomic groups.

ASD is often characterized by unique and atypical behaviors, including hand flapping and rocking; self-injurious behaviors, such as biting or head banging; hitting or kicking others; and temper tantrums (Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). These behaviors are frequently mistaken to be aggressive actions or the result of poor parenting (Gray, 1993, 2002; Green, 2003; Thibodeau & Finley, 2017). Families and caregivers of individuals with ASD might also encounter courtesy stigma, the negative attitudes and behaviors from others as a result of caring for someone with a stigmatizing condition (Cantwell, Muldoon, & Gallagher, 2015). As such, many families describe feeling stigmatized by members of their extended family, their existing social networks, and society at large. This stigma can be enacted when the negative treatment an individual receives is the result of a stigmatizing condition, or felt when the treatment results in feelings of embarrassment and shame (Broady, Stoyles, & Morse, 2017).

Families of cASD might experience further marginalization due to health disparities, including challenges with access to care (Tregnago & Cheak-Zamora, 2012), finding appropriate HCP who can meet their needs (Angell, Frank, & Solomon, 2016; Muskat et al., 2015; Stein, Polido, & Cermak, 2012), and financial hardships due to out-of-pocket medical costs not covered by insurance (Tregnago & Cheak-Zamora, 2012). In fact, parents of cASD report that they struggle to find a medical home; if they are fortunate enough to find one, they often feel they have to make concerted efforts to get quality care, with several practitioners failing to refer them for specialty services (Brachlow, Ness, McPheeters, & Gurney, 2007). In addition to difficulties accessing care, parents of cASD also struggle with finding HCP with experience in working with this population (Krauss, Gulley, Sciegaj, & Wells, 2003; Muskat et al., 2015; Stein Duker et al., 2017).

Health disparities for cASD are compounded when intersectional identities are considered. “Intersectionality” is a term originating from women’s studies and is used to describe the “interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements and cultural ideologies and the outcomes of these interactions” (Davis, 2008, p. 68). Some of the challenges families of cASD experience are

exacerbated by race, ethnicity, and/or socioeconomic status. For example, one study found that Latino families with cASD encountered barriers (e.g. lack of culturally tailored information), which affected the timing and quality of services (Blanche, Diaz, Barretto, & Cermak, 2015). Similarly, another study found that urban African American families experienced unequal treatment in health care, which at times resulted in delayed diagnosis and administration of appropriate treatment of ASD (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015). The impact of these intersections provides an important foundation for understanding how disparities are intensified for segments of the population.

As our nation attempts to adapt to an increasingly diverse society, the field of health care has recognized the need to create a more competent workforce to better address health disparities (Cohen, Gabriel, & Terrell, 2002; Grumbach & Mendoza, 2008; Mitchell & Lassiter, 2006). This includes training programs to educate future HCP on appropriate communication methods for patients from various cultural backgrounds (Murray-García, Harrell, García, Gizzi, & Simms-Mackey, 2014), and programs to recruit medical students from minority backgrounds (Garces & Mickey-Pabello, 2015). These efforts to diversify and educate the medical workforce also aim to minimize the impact of implicit (unconscious) bias. The Institute of Medicine defines unconscious bias as unrecognized preconceptions or prejudices held by an HCP toward members of a social group, such as racial minorities or those diagnosed with a disability, that might influence patient-provider communication or the care offered to those individuals (Smedley, Stith, & Nelson, 2003). However, despite changes in training and education (Paul, Ewen, & Jones, 2014), many HCP lack experience and/or instruction specific to working with individuals with ASD and their families, and problems with implicit bias persist.

2 | METHODS

2.1 | Design

The data reported in this study were part of a larger mixed-methods, sequential, explanatory design in which qualitative descriptive data were collected and analyzed in order to explain and elaborate on quantitative data previously collected (Creswell & Plano Clark, 2011; Sandelowski, 2000; Stein et al., 2012; Stein, Polido & Cermak, 2013; Stein Duker et al., 2017, 2019).

2.2 | Study participants

This qualitative study included two 3 hr focus groups of seven dental professionals with experience treating cASD. The focus groups took place in Southern California and consisted of dental practitioners with at least 1 year of experience working with children with special healthcare needs who had treated at least eight cASD in the previous year. Purposeful recruitment of dentists known to the study team was conducted initially, followed by snowball sampling, where dentists provided recommendations for other potentially eligible dental professionals. A total of 11 providers agreed to participate in one of two focus groups; seven dental practitioners ultimately participated.

2.2.1 | Data collection—The focus group discussions were convened as a part of a larger study exploring dentists' perceptions of working with cASD and the oral care-related challenges experienced by cASD. Semistructured interview questions included prompts about oral care challenges, as well as strategies used to improve care (Stein et al., 2012, 2013; Stein Duker et al., 2017, 2019). Questions were created by the authors and then reviewed and edited by a pediatric dentistry expert and a qualitative research expert.

Each focus group had four participants; one dental practitioner was present at both sessions. Groups were kept small to allow participants multiple opportunities to share in the discussion, as they were believed to have a great deal of insight to contribute to the oral care of cASD. To begin each focus group, the moderator provided a brief overview of the purpose of the study and then proceeded to utilize the semistructured questions. Each focus group lasted approximately 3 hr, was digitally recorded, and was transcribed verbatim. The participating HCP are described in Table 1.

2.3 | Data analysis

Thematic analysis was utilized to code the transcripts (Vaismoradi, Turunen, & Bondas, 2013). Members of the research team independently read and coded a single focus group transcript, followed by the development of a preliminary list of codes and subcodes developed inductively from the data. The original transcript was then independently coded a second time using the list of codes and then compared with other team members. This process was repeated for the second focus group.

During the analytic process, the primary coders (the first two authors) observed subtle, nuanced themes related to alienation and othering language used by the dental professionals. Additional codes, developed inductively from the data, emerged related to the unconscious biases of dentists when discussing cASD and their families; these are the data presented in this study. Drawing from their personal experiences encountering implicit bias as researchers/practitioners working with children with special needs, and related to their own ethnic minority status, the two primary coders were attuned to identifying these nuances as they arose in the transcripts. During this secondary coding process, coders were informed by the interpretive approach to oral narrative, referred to as “dialogic analysis”, which is especially useful for analysis that requires close attention be paid to the setting, social circumstance, and context of the information, whether “interactional, historical, institutional (or) discursive” in order to interpret the data (Riessman, 2008, p. 105).

2.4 | Rigor and trustworthiness

Given the nuanced nature of these data, the authors discussed their own biases and reflected on how these might influence their analysis in peer debriefing groups. Although no author has ASD or has a child with a diagnosis of ASD, all have varying degrees of experience working with children diagnosed with ASD and their families. Some also acknowledge that they have observed or have been the recipient of implicitly biased language in other settings. To enhance trustworthiness and ensure that the authors' personal experiences did not influence analysis, triangulation was utilized and themes were coded independently by a third coder (third author), and subsequently reviewed by all members of the research team

for congruence (Padgett, 2012). Discrepancies in coding were resolved through discussion until consensus was reached.

2.5 | Ethical considerations

The study was approved for human subjects by the Institutional Review Board of the University of Southern California Health Sciences (no. HS-11-00733). All participants were provided with written and oral information about the study and gave informed consent prior to study participation.

3 | RESULTS

Three themes regarding the hidden assumptions of healthcare professionals emerged: (i) healthcare microaggressions; (ii) marginalization; and (iii) preconceptions.

3.1 | Healthcare microaggressions

Healthcare microaggressions reflected instances when the HCP described patients in a manner that communicated subtle, seemingly unconscious, negative opinions of them. These included statements both about cASD, as well as their families. For example, when discussing encounters with cASD, participant B2 said:

There are different triggers for different patients. Pediatric dentistry [for cASD] is a minefield... You've got to know where the land mines are that you're going to have to avoid.

This is a problematic statement, because the use of the metaphor of a minefield denotes that providing care for cASD is dangerous, not necessarily in a literal sense but that one must “tread lightly”, being careful to avoid “setting them off”. Another example of words highlighting an underlying negative view is through participant B2's retelling of a discussion with a colleague about the possibility of expanding their practice to include a special needs population and how this might be profitable “with your handicap stuff that could be really good (way to make more money).” Whether the use of the phrase “handicap stuff” was chosen to describe the patients or the practice, it is telling of an ostensibly negative regard for this population. Disability rights literature highlights how the use of the term “handicap” fell out of practice in the mid-1980s and was replaced by the term “disability”, and was embraced by those it was meant to describe because it was thought to be more empowering by focusing on ability rather than deficits (Devlieger, 1999).

The larger family unit was also sometimes the target of healthcare microaggressions. For example, participant A3 described a scenario in which a desensitization strategy was used to prepare the patient for their impending visit, requiring several visits over time to acclimate the patient to the setting and the expectations. This participant stated: “I'd ask the parent, ‘you know, come on, I've done this 15 times, can you pay for like one office visit?’”. This highlights the frustration this provider felt providing the extra client-centered care that was required to achieve success with this particular patient.

3.2 | Marginalization

The marginalization theme exemplifies the use of exclusionary language, such as “those kids”, to create a sense of otherness and distinction among patient populations, specifically identifying cASD as different from typical patients. This is evident in a story participant A3 disclosed:

So I share an office with another dentist who is not all for that kind of huggy, feely, screamy, kicky kinds of families that I have, so I work on...the Mondays are my special needs day...Thursday, I have a private practice, no special needs patients. I do see a couple (of) special needs patients that are quiet and are not going to make a fuss and are not going to be screaming, yelling, but Mondays are a very, very loud day for us.

In this case, there is a distinction made between children with special needs and children without, down to the day with which they can receive care. The argument could also be made that this provider is working to accommodate special needs patients within the limitations of their resources. However, this might have been a missed opportunity by the provider to advocate for patients with special needs to limit othering by colleagues. Even in the dialogue of the most well meaning HCP, marginalization can infiltrate discourse. Another provider (A4) expressed that delivering treatment to cASD who are non-verbal is best served when they are treated equal to children without disabilities. Participant A4 then goes on to say: “They communicate, and I have found that in treating them like that, it makes them feel like they are just like everybody else.” Participant A4 does not say that they “are equal” to everybody else, but instead that they “feel” like they are. In another example, participant B3 uses the term “them” to describe his patient clientele: “We see a whole bunch of them, because they do not have a lot of people out there that will provide them care”. For populations that are already marginalized and stigmatized, using “them” can be viewed as dismissive or othering language, whether intended or not.

Families were not exempt from this type of sidelining language. As participant B3 emphasized, parents of cASD are at times required to take the care they can get for their children, stating that:

I don't find that they (parents of a cASD) have a problem if you charge them a little more for spending that time (with their child). They're just grateful that there is somebody who will spend the time with their child and take care of their child.

This undue expectation that parents of cASD would have to spend more for quality care is an unfortunate reality for many families and contributes to the feelings of stigma and lack of access that many face when attempting to access resources in the community.

Another example of marginalization can be seen in participant A3's recollection of an encounter when the topic of general anesthesia was broached with a parent, recalling that “She refused for a year and half to put her (daughter) under general anesthesia and I threatened, I told the regional center I'm going to have to send her to social services for child endangerment and then she agreed to put her under general anesthesia”. This statement is particularly concerning given that the dentist is operating from a position of influence and power to persuade this mother to make the decision to utilize general anesthesia, which itself

comes with medical risks, such as errors related to dosage and medication monitoring that can have fatal results (Lee, Ayers, & Kronenfeld, 2009). Medical professionals are often held in high esteem and thought to be experts who are all-knowing; therefore, their recommendations matter. The threat of social services only increases that power differential between patient and provider. Marginalized people often find this power dynamic to be difficult to circumnavigate.

3.3 | Preconceptions

The HCP expressed statements which illustrated the unconscious biases and opinions they held about their patients with special healthcare needs. These preconceptions were brought to their interactions with patients and their families and included assumptions about the caregiver's willingness to participate in their child's oral care needs, as well as about patients' cultural backgrounds. For example, when participant B2 shared personal thoughts on general anesthesia with the group, his personal views about patients' parents were exposed:

My personal thoughts, I do not like putting them to sleep unless they have dental needs...so for just cleaning...I do not think that parents should rely on the fact that I can put them to sleep every 6 months. Because I think parents think, "I'm not going to clean their teeth because (the dentist) can just do it in 6 months".

The assumption made here is that parents are relinquishing their oral care-related responsibilities in their child's health care. Another HCP (B1) supported this preconception, stating that parents of children with special needs are less inclined to worry about their child's preventive dental care, because "A lot of times, unfortunately your teeth are not important. A lot of people don't think it's important. Especially parents of special needs kids. (It is) the last thing on their mind".

These preconceptions were not exclusive to healthcare needs and beliefs, but also extended to ethnic groups. For example, one HCP (B1) told a story about demonstrating culturally competent care by tailoring her language in interactions with Hispanic families, stating: You never tell a little Hispanic kid that he's going to feel a little pinch, because the parents in Hispanic families often pinch their kids as punishment, and so the white kid you can tell him sometimes you'll feel a little pinch when we give you the anesthetic.

Despite the provider's assuredness, this is not a universally held belief among Hispanic and Latino families. In fact, this stereotype is not supported by scientific literature, nor a regular Internet search, nor from the second author's personal experiences growing up in a Latino household. This quote demonstrates how misinformation can lead to falsely held conventions.

4 | DISCUSSION

The three themes that emerged from the data of these two focus groups with HCP reveal how communication can be influenced by previously held biases and assumptions. Unconscious (implicit) bias typically occurs in an unintentional manner and can be activated unknowingly by situational cues, often without a person's intent or awareness (Blair, Steiner,

& Havranek, 2011). We are most interested in the subtle, nuanced, and contextually situated hidden assumptions that might expose themselves when individuals are provided the opportunity to dialogue without the concern for formality.

Despite training to address the problem of implicit bias, research continues to show that stereotypes influence how some patients are cared for by HCP (Bean, Stone, Moskowitz, Badger, & Focella, 2013; Blair et al., 2013; Sabin, Marini, & Nosek, 2012). For example, one study found that pediatricians' implicit attitudes and racial stereotypes about their patients were associated with treatment recommendations (Sabin & Greenwald, 2012). When Caucasian pediatricians indicated that they believed African American patients were less medically compliant, the pediatricians were less likely to agree to prescribe narcotic medication for pain, even when considered best practice (Sabin & Greenwald, 2012). According to the National Committee for Quality Assurance (2016), health disparities continue to persist for several groups, including individuals with disabilities who have decreased access to healthcare services and lower quality care, and therefore experience poorer health outcomes.

The concept of unconscious bias permeating language is not a new idea. The term "microaggression" was originally coined in 1978, but popularized later to describe covert racism, or the "brief, everyday exchanges that send denigrating messages to people of color because they belong to a racial minority group...(they) are often unconsciously delivered in the form of subtle snubs or dismissive looks, gestures and tones" (Sue, Capodilupo, Torino, & Bucceri, 2007, p. 273). While predominately used to refer to issues surrounding race, it is the subtle, covert, and unconscious delivery that we identified as denigrating messages toward cASD and their families.

One might question why these seemingly innocuous statements are concerning. The answer, simply put, is that language matters. Not only is word choice important, but so too are the context and the history carried with them, especially for groups that are vulnerable. There is evidence to suggest that unconscious bias can be transferred to patients, regardless of the provider explicitly activating and acting on such behaviors (Blair et al., 2011; Chapman, Kaatz, & Carnes, 2013). That is, the power of the bias is relayed in the word choices of providers and unspoken actions of HCP, and these biases and assumptions might affect patient-provider rapport and subsequent treatment. Through language, misinformation can spread and biases can grow; if left unchecked, misinformed biases could lead to more opportunities to stigmatize others, especially in healthcare settings.

As our HCP suggest, parents of cASD might be forced to pay higher costs for their child's care; this is supported by caregivers as well (Stein Duker et al., 2017). Likewise, Kogan et al. (2008) found that families of cASD and special health care needs were more likely to need additional income for their child's medical care and report financial problems. In another study, researchers found that over 34% parents of children with special health care needs spent over 3% of their income on healthcare needs of their child with ASD (Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Families with financial flexibility were able to navigate the system, but were still unable to escape the increased costs; for others, the higher costs served as a barrier to accessing quality care. These financial difficulties create

additional burdens for parents, making them pay different fees due to their child's ASD diagnosis, and might increase the stigma felt by this population and perpetuate health disparity.

It is well documented that cASD and their families experience stigma and marginalization as a result of their diagnosis, but less is known about HCP biases toward this population. Evidence suggests that marginalized groups are susceptible to persistent health disparities when practitioners exhibit biases. Literature of ethnic minority groups and biases provide a point of reference for comparison. In a systematic review, low-to-moderate levels of HCP implicit bias were found toward ethnic/minority patients in all but one of the 15 studies; bias was significantly associated with patient-provider interactions, treatment decisions, adherence, and health outcomes (Hall et al., 2015). The results of our paper are consistent with findings related to HCP implicit bias when working with marginalized populations; in this case, cASD and their families. Further research is needed to explore the nature of this bias and how it might impact quality of care.

4.1 | Implications for future healthcare provider training

As the healthcare field continues to target the objective of creating culturally competent care to combat the pervasive nature of many healthcare disparities, it is crucial that HCP training include foundational preparation for treating diverse populations (American Medical Association, 2016; Paul et al., 2014; Smedley et al., 2003). Despite this increased emphasis on cultural competency training and didactic and clinical instruction on how to work with cASD, families and caregivers of individuals with ASD continue to report struggling to find providers who are trained to and willing to work with their child with special healthcare needs (Muskat et al., 2015; Stein Duker et al., 2017). Based on our results, the unconscious bias represented in language was observed in both older and younger dentists, across generational and educational levels. Therefore, the presence of bias continues to be a problem, and even highly experienced HCP could benefit from training in cultural competency to ensure that their language, actions, and practice align for the betterment of their patient.

4.2 | Limitations

The results presented are from a secondary analysis of our data and do not represent consensus opinions of all of our focus group participants, but rather statements made by some of the HCP. The findings represent the subtle undertones in the language used by some providers to refer to their patients, and were not part of the interview questions; as such, there was not an opportunity to explore whether participants' comments were offhand statements or reflections of deeply held beliefs. However, providers seemed to feel comfortable speaking about their patients and experiences, which resulted in a glimpse into some of their hidden assumptions.

Additionally, focus groups were only conducted with one type of HCP; HCP in other fields might hold different assumptions of cASD and their caregivers. Lastly, it is not clear the extent to which the language the providers used in the focus groups was similar to what they say in clinical encounters. However, research does show that perceived, as well as overt,

discrimination in HCP language and behaviors are associated with negative mental and physical health outcomes in diverse patient populations (Lee et al., 2009; Tajeu et al., 2015).

4.3 | Conclusion

The lives of cASD and their caregivers could be affected by the stigma they experience in healthcare settings. In presenting examples of assumptions embedded in HCP language, we aim to raise awareness about the significance and consequences of biased communication in the patient–provider relationship. Self-reflection and training about the importance of language choices used with vulnerable populations might serve to decrease the barriers to care that many encounter as they access healthcare resources. Further research is necessary to clarify what these assumptions mean and how they relate to quality of care and inform practice standards. Additional research is required to elicit consumer perceptions of how HCP biases and assumptions impact patient–provider relationships.

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TABLE 1

Descriptive characteristics of focus group participants

Participant identifier	A1	A2	A3	A4 ^a	B1	B2	B3
Focus group number	1	1	1	1/2	2	2	2
Specialization	Pediatric dentistry	Pediatric dentistry	General dentistry	Pediatric dentistry	Pediatric dentistry	Pediatric dentistry	Pediatric dentistry
Postgraduate training	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Highest degree earned	DDS	DDS	DDS	DDS	DDS	DDS	DDS
Participated in a residency that specialized in CSHCN	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Method of education received in school about treatment of CSHCN	Lecture only	Lecture & Hands-on	Lecture & Hands-on	Lecture only	Lecture & Hands-on	Lecture & Hands-on	None
Feel prepared to work with CSHCN (following pre/postgraduate education)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Feel prepared to work with children with ASD (following pre/postgraduate education)	Yes	Yes	Yes	No	Yes	Yes	Missing
Years in practice	32	29	14	30	2	21	33
Years in practice with children	32	29	14	28	2	21	33
Frequency of treatment of CSHCN	Often	Often	Very often	Very often	Very often	Very often	Very often
Frequency of treatment of children with ASD	Occasionally	Often	Very often	Very often	Often	Very often	Very often
Number of children with ASD treated in the past 2 years	10	50+	“Tons”	500	50+	Hundreds	100+

^aParticipant A4 attended both focus groups.

ASD = autism spectrum disorder; CSHCN = children with special health care needs; DDS = Doctor of Dental Science.