

Introduction

Abstract

Being diagnosed with Autism Spectrum Disorder (ASD) gives clients access to resources such as accommodations in a school setting or access to beneficial therapies such as Applied Behavioral Analysis (ABA) therapy. However, it is difficult for many people with ASD to gain access to said resources due to the occurrence of misdiagnoses. The phenomenon of the misdiagnosis of ASD primarily impacts Black people. Factors such as limited access to mental health professionals coupled with professionals' lack of cultural responsiveness (CR) and cultural humility (CH) towards Black people can increase the chances of a Black person with ASD being misdiagnosed with a different, possibly more severe, disorder.

Aims of the Research

This study aimed to gain more insight into the experience of Black people with ASD who have been misdiagnosed with a different disorder by identifying common diagnosis barriers faced by participants that led to their misdiagnosis. Barriers include Black people with ASD feeling a lack of connection to their healthcare professionals. Previous studies have discussed this using cultural humility (CH) and cultural responsiveness (CR) as a framework to understand the disconnectedness between Black people with ASD and their healthcare professionals. This research is important because it highlights the challenges Black clients face when it comes to accessing quality care.

Definitions

Cultural Humility (CH): Understanding that other people are the experts on their own culture. Involves an openness to learning about other’s culture(Broder-Fingert et al., 2020; Straiton & Sridhar, 2021).

Cultural Responsiveness (CR): Being aware of the challenges that someone may face due to their cultural identity and using this knowledge to interact with them accordingly. Adapt to the cultural needs of others (Broder-Fingert et al., 2020; Straiton & Sridhar, 2021) .

Research Questions

- RQ1: What are common barriers faced by Black clients with ASD who have been previously misdiagnosed with more severe disorders?**
- RQ2: How does the occurrence of a misdiagnosis affect a Black client with ASD’s perception of psychological care and treatment?**

Method

Research Design

This study used a mixed-methods design. The quantitative portion of the study was used for screening purposes. It covered characteristics such as demographics, diagnosis history, and participation eligibility and interest.

The qualitative portion of the study included a 12-item structured interview. The interview asked participants about their experience with receiving their diagnoses, their experience receiving and managing their ASD diagnosis, as well as their experience with their clinician. The goal of the interview was to get a better understanding of participants experiences with mental health care.

- Sample Questions**
- *How would you describe the relationship or connection between you and your diagnosing clinician during this process?*
 - *How would you describe your reaction to this your diagnosis?*

Participants

Participants were at least 18 years of age, identified as Black, have a current/recent ASD diagnosis and were previously diagnosed with one of three qualifying disorders: a schizophrenic spectrum disorder, borderline personality, and bipolar disorder. This study had 3 participants.

- Participant Information**
- *P1: Misdiagnosed with Schizoaffective Disorder for under a year*
 - *P2: Misdiagnosed with Bipolar Type 2 for 4 years*
 - *P3: Misdiagnosed with Schizotypal Disorder for 2 years*

Data Collection and Analysis

Participants who completed the screening survey contacted for a follow up interview. A codebook was created, and each interview was reviewed and highlighted based on said codebook. Interviews were then compared to identify common experiences amongst participants.in each interview were compared to the responses of other participants to identify common themes and experiences.

- Sample Identified Codes/Themes**
- *Feelings towards the health care system*
 - *Affect of misdiagnosis*
 - *Symptoms*
 - *Familial/Clinical Support*

Results

Conclusion

Codes Identified	Participants ID
Barriers Faced	
Lack of Access	P1,P2,P3
Confusion with Clinical/Diagnosing Process	P1,P2,P3
Poor Connection with Clinician (Misdiagnosis)	P2,P3
No CR/CH Present as Perceived by Participant	P3
Different Racial Backgrounds (White)	P1,P3
Resolved Barriers/ Protective Factors	
Familial Support	P1,P2,P3
Agreeable Clinician	P1,P2,P3

All participants expressed a better relationship with their second clinician when compared to the relationship they had with their first clinician. 67% of participants had a Black clinician for their ASD diagnosis.

All participants expressed being afraid of judgement from their friends and family following their initial diagnosis, as well as their clinician. Participants also stated that this fear of judgment was present when interacting with other and future health care/ mental health professionals.

Discussion

Education needs to be reformed for both clients and practitioners. A lack of knowledge about the mental health care system can lead to clients becoming complacent when speaking to their clinicians. Additionally, Black clients who have had negative outcomes from advocating for themselves, might be fearful of being judged or misunderstood for speaking up and advocating for themselves, which leads to complacency. This anxiety can also lead to Black clients being more reserved and “stand-offish”. These behaviors is often used as diagnosis criteria for more severe disorders. Overall, anxiety experienced by Black clients dealing with the health care system can affect misdiagnoses. It is important for practitioners to have knowledge of how cultural groups interact with authoritative figures, as well as how symptoms differ to prevent misdiagnosis.

Additionally, the misdiagnosis of Black clients impacts their access to an inclusive and quality education. ABA therapy is the most popular intervention for people diagnosed with ASD. Most school aged clients receive ABA referrals through the school they attend. However, these resources cannot be offered to clients if they are misdiagnosed with another disorder such as bipolar disorder. Similarly, students who need an IEP or 504 plan to be successful in school may not have access to these accommodations due to their misdiagnosis. ASD qualifies for these resources, however, the disorders represented by participants do not directly qualify for an IEP or 504 plan. Thus, students and their families have to take extra steps to get the support needed.



The research reported here was supported by the Institute of Education Sciences, U.S. Department of Education, through Grant R305B210014 to Florida State University. The opinions expressed are those of the authors and do not represent views of the Institute or the U.S. Department of Education.