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Autism in Adolescents and Young Adults: Experiences, Challenges and Research Gaps in Black and Caribbean Populations

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Purpose

The purpose of this literature review is to examine the experiences and outcomes of adolescents and young adults living with ASD between the ages of 13 and 30, specifically in Black and Caribbean populations. This review will aid in understanding how ASD affects development, communication, and social and cognitive skills in everyday life. Furthermore, it will help identify the challenges that adolescents and young adults may face. The findings may contribute to greater awareness, early intervention practices, and improvement in diagnosis. In addition, gathering this information will support recommendations for an upcoming research project in St. Kitts and Nevis. This will create a greater understanding of existing research in the field, provide an in-depth understanding of the experiences of young people from diverse cultures, countries, and circumstances, and help to identify research gaps and inform the literature's methodology. The literature review consists of articles on ASD that highlight multiple gaps in research for Black and Caribbean populations between the ages of 13 and 30, which underscores the need to expand research for underrepresented populations.

Introduction

Over time, ASD has gained greater recognition and become more recognisable and prevalent. The clinical significance of ASD has expanded in recent years, considering the high increase in prevalence among adolescents (Drusedau et al., 2023). According to the 2019 Global Burden of Disease (GBD) estimates, autism spectrum disorder has a profound impact (Yan, 2024; Li, 2024). Solmi stated in 2019 that more than 28 million people worldwide were affected, although the prevalence of ASD is highest in high-income regions such as North America (Solmi, 2022). ASD is a neurological and neurodevelopmental condition that affects social skills, development, sensory processing, communication, and behaviour. Current literature has displayed relationships between social communication, cognitive skills, language, and functional impairments in individuals with ASD (Bhat, 2020). Signs of ASD can be shown in early childhood but can also become evident in later stages of life. The understanding of ASD in adolescence and young adulthood is important because it allows advocates, researchers, health professionals, and educators to gain insight into the challenges they experience in daily life. Furthermore, transitioning from adolescence to adulthood can be difficult, and individuals with ASD may struggle with adapting to changes in routine. The increasing prevalence of autistic young adults indicates that a significant portion within the community may encounter a lifetime of disadvantage because of limitations to resources and support for their autism (Pillay et al., 2022). Understanding how this transition impacts young people with ASD can enable targeted support to be developed to make this transition as smooth and successful as possible.

ASD is a disorder that affects individuals of all races and backgrounds. However, because of long-lasting health disparities, Black and other minority populations are more likely to lack access to resources and support compared to other population groups (Angell et al., 2018;

Bilaver et al., 2021). Findings from a study revealed that ASD was most prevalent among White children in the 1990s but is now most prevalent among Black, Hispanic, and Asian/Pacific Islander children (Maenner, 2023; Nevison & Parker, 2020). Black and Caribbean populations are underrepresented in research, creating a gap in understanding the impact of race and culture on the ASD experience, resulting in delayed diagnoses, limited services, and minimal resources for early intervention, creating barriers to accessing care and support. This is because strong cultural beliefs may exist within Black and Caribbean communities that can influence recognition of ASD. The way these communities perceive healthcare services and the level of trust they have in the healthcare system cause delays in help-seeking, thereby delaying diagnosis and access to support services. This literature review aims to explore the challenges and outcomes of young individuals with ASD in Black and Caribbean populations by identifying best practices for improving awareness, developing better support systems, and discerning gaps in research and understanding that need to be addressed.

Overview of the Literature

Several studies conducted in the United States, the United Kingdom, South Africa, Germany, Australia, Jamaica, Lebanon, and Latin America have found that many individuals with ASD face challenges that impact daily life. Some of these difficult experiences may involve social relationships, access to healthcare and diagnosis, mental health and well-being, and family support, from adolescence to the transition into adulthood. Feedback from young participants aged 7 to 14 in a study in Germany indicated that training during group therapy sessions can strengthen communication and friendships, helping individuals develop coping mechanisms that support daily living (Drusedau et al., 2023). Findings from a post-training questionnaire revealed that adolescents could communicate more effectively, maintain friendships successfully, and better understand their feelings (Drusedau et al., 2023). Accompanying activities, such as role play, character development, and creative art to target social competencies, can be used to improve outcomes for individuals with ASD (Zhang et al., 2026). These positive experiences aid in increasing social interactions among individuals with ASD, improving well-being and mental health outcomes. Despite improvement in social skills, evidence has shown several challenges with mental health while transitioning into adulthood with ASD, especially after the effects of COVID-19. Numerous mental health challenges have emerged due to the COVID-19 outbreak and lockdowns, which potentially negatively affected the care-leaving transition of young people with intellectual disabilities (Mupaku et al., 2021). This resulted in regression of independence and an increase in dependence on caregivers. Anxiety symptoms and disorders are the most prevalent mental health challenges experienced by autistic people overall, across the lifespan (Chuan-Lai, 2023). Other common mental health challenges for individuals with ASD include depression, ADHD, schizophrenia spectrum and other psychotic disorders, and bipolar disorder, which have shown increasing prevalence over recent decades. With these mental health conditions rising in prevalence, this intensifies the limitations of healthcare services. These challenges add to systemic barriers to healthcare services, an ongoing disparity for Black and Caribbean populations.

Insights have indicated that Black and Caribbean populations face numerous challenges accessing services. Evidence of implicit bias is also present in the assessment and diagnosis of autism. For example, several studies examining the experiences of parents of colour found that provider bias and providers' dismissal of parental concerns impede access to timely

assessment and diagnosis (Dababnah, 2018; Voliovitch, 2021). This results in a higher prevalence of misclassification of intellectual disabilities in comparison to White populations. Discoveries from studies have revealed that following an ASD diagnosis, limited resources and access to services were given, leading Black parents/guardians to be uncertain and confused about the next step. This can delay early intervention, contributing to greater difficulties for individuals with ASD. Early intervention is crucial because it can reduce negative behaviours, improve social and cognitive skills, and promote development that contributes to positive educational experiences. Findings have also highlighted how sensory feeding issues can result in developmental delays, communication issues, and increased problematic behaviours. Certain ASD behaviours are due to developmental challenges and can interfere with academic progress, leading to low educational attainment.

Following the transition into adulthood, findings have shown that individuals with ASD tend to fall into the lowest income brackets, with the highest rates of non-participation in activities post-school (Wehman et al., 2014). In addition, compared to males with ASD, females may encounter a higher risk of fewer employment opportunities, economic instability, lower wages, and reduced hours (Lindsay et al., 2018). Findings indicate that young adults face limitations not due to their individual difficulties, but to systemic barriers related to support from schooling, post-high-school extracurricular activities, and the transition to adulthood in the community (Pillay et al., 2022). Results from studies have also shown that post-school outcomes for adults with ASD are generally unfavourable, potentially hindering their ability to integrate into adulthood successfully. Support involvement within communities is also deficient in terms of resources and programmes that are designed to improve the quality of life for individuals with ASD. This may lead to regression of independence and additional caregiver responsibilities. In addition to inadequate community support, caregivers may experience a lack of family support for several reasons.

Critical Analysis of the Literature

Various research methods were employed in the studies that were included in our literature review, such as qualitative, quantitative, and mixed methods, to provide a comprehensive analysis. Additionally, self-assessments, focus groups, interviews, surveys, and questionnaires were used. Some studies used popular assessment methods, such as the Quality-of-Life questionnaire (QoL), the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Observation Schedule (including the second edition), and the Ritvo Autism and Asperger Diagnostic Scale (RAADS-14) for early intervention and as they develop. QoL is a questionnaire tool that supports the assessment of an individual with ASD by considering their culture, values, and well-being, providing insights into life experiences. Study findings displayed that CARS was utilised in Jamaica for the accuracy and diagnosis of ASD; however, it was not designed to evaluate cultural adaptation, with minimal adaptations to language barriers for the population to fully understand (Samms-Vaughan et al., 2017). RAADS-14 is a diagnostic tool specifically for adults that includes psychometric properties and focuses on sensory differences, which lacks representation in autistic traits (Baghdadli et al., 2017; Riccio et al., 2020). Although the use of these methods potentially allows young adults to express the challenges of living with ASD and navigating the transition into adulthood, gaps were evident. These approaches enabled insights into personal experiences, promoting greater understanding of the barriers and challenges faced by adolescents and the progression into adulthood.

Although the sample sizes in these studies were adequate, they could have been larger considering the rising prevalence of diagnoses. Larger sample sizes, depending on the type of research (quantitative), can improve the accuracy and reliability of studies and allow findings to be generalised more accurately because they better reflect the diversity of the true population. Most studies were conducted in higher-socioeconomic-status countries due to better access to resources compared to low- and middle-income countries. In low- and middle-income countries, early diagnosis and intervention remain a significant concern given the scarcity of resources (Samms-Vaughan, 2017). Research is very costly, requiring significant funding, resources to support data collection and analysis, and incentives to increase participation. Therefore, a lack of funding and resources can cause restrictions on studies of ASD, especially in Black and Caribbean populations that experience several limitations and systemic racism, creating a bias in existing data because it only reflects the experiences of high-income Western countries. A variety of factors contribute to why these communities are underrepresented in ASD research, and this limits our understanding of how issues like cultural beliefs, lack of family support, and a history of health disparities may impact Black and Caribbean communities affected by ASD.

Gaps in the Literature

Several gaps were identified in the ASD literature. Higher-income countries with predominantly White populations have greater access to conducting research compared to lower-income countries, especially those in the Caribbean, which face limitations. While reviewing the literature for ASD in the Caribbean population, many studies were outdated, highlighting the lack of research within the past decade. Furthermore, findings for ASD were more accessible in Latin countries in the Caribbean compared to predominantly Black populations, displaying the ongoing disparities even within Caribbean countries. The underrepresentation of Black communities in research results hinders our understanding of the impact of ASD on diverse populations.

Another significant gap in the literature was the underrepresentation of females participating, which restricts perspectives on how ASD affects them and results in gender inequality in ASD research and understanding. Underdiagnosis in females may result from often showing less stereotyped motor behaviours, overt restricted interests, and masking techniques (Tsirgiotis et al., 2021). This underscores the critical need for further research to improve outcomes for females with ASD, awareness, and advocacy for Black and Caribbean populations. A further concern with the studies in the literature review was greater participation from a parent or guardian rather than the individual with ASD, which limits the ability of researchers to obtain the true perspective of young people living with autism. Findings also revealed that some parents postpone disclosing that their children are autistic until they feel they are ready; however, evidence from a study suggests that earlier disclosure has more positive outcomes (Oredipe et al., 2022). Several factors contribute to the lack of representation of individuals between 13 and 30 living with ASD, and these may include the affected individual being nonverbal, having limited speech, anxiety, a lack of confidence, and difficulties with understanding surveys and questionnaires. Legal guardians' input always matters and provides great insights; however, it can lead to inaccurate findings. A more inclusive methodology needs to be explored to ensure that we can ethically and effectively include young people living with ASD in research studies.

Implications for St. Kitts and Nevis

As a Small Island Developing State (SIDS), St. Kitts and Nevis is a sparsely populated country with growing numbers of individuals with ASD who have limited access to care services and resources. Difficulties were encountered in finding published articles or research papers for St. Kitts and Nevis during the literature review, underscoring the limitations that the island endures, which emphasises the need for research to be conducted to gain true insights into the life experiences of individuals with ASD. Limited research and resources can lead to delays in diagnosis, early intervention, and other support services for research to assist with living with ASD in St. Kitts and Nevis. Resources for diagnosis are scarce, intervention teams are limited, and minimal research exists to examine the prevalence of ASD and developmental profiles in small island nations (Whittaker et al., 2025). Additionally, inadequate knowledge of the neurodevelopmental condition may increase stigma, unawareness, discrimination, and lack of understanding within families and the community. These challenges that individuals with ASD face can negatively impact their overall quality of life. Providing more resources to expand existing research will address systemic barriers, promote awareness, and increase inclusivity within diverse populations.

Like Black populations in other countries, there have been consistent trends such as racial health disparities, discrimination from health professionals, and cultural stigma as they relate to challenges that many Caribbean families face, even with a higher socioeconomic status, relating to ASD. This stems from the history of health disparities, cultural beliefs, and deficiencies in education from different Black backgrounds. To improve the outcomes and quality of life of young people and adults with ASD in St. Kitts and Nevis, local research is pivotal. Expanding research can facilitate the identification of specific challenges the island faces, and the restructuring of policies implemented to improve resource allocation.

Recommendations for the Upcoming Research Project

A collection of studies had success in focus groups and interviews among individuals with ASD. Not only were these methods beneficial, but they also improved social and communication skills. Using focus groups to include members of the ASD population, especially young adults, helps them recognise that they are not alone and increases their confidence to voice their challenges and experiences as they transition into adulthood. As these individuals transition into adulthood, psychosocial services should be considered essential (Mupaku et al., 2021) to increase positive outcomes. Findings from studies suggest that there is a need for targeted transition planning for young adults with ASD to address barriers in employment and participation in activities post-school (Pillay et al., 2022). The use of surveys is also a great source to collect data for adolescents and young adults; nevertheless, many individuals with ASD have a delay in cognitive skills; therefore, surveys should be straightforward. Furthermore, developing interventions should incorporate language barriers and the use of visual support to promote greater comfort and understanding for participating Black individuals with ASD (Davis et al., 2024). Research should also analyse how cultural and religious beliefs, language barriers, and practices can contribute to misinterpretations. Having a diverse group of culturally competent researchers is essential to building partnerships within communities, building relationships and trust for individuals with ASD, reducing systemic barriers, and increasing research participation (Maye et al., 2021).

In addition, this can aid in allowing inclusivity for all individuals on the spectrum to receive more insights into experiences and constraints. Researchers should also develop creative, interactive, and enjoyable methods to encourage individuals to participate in focus groups, interviews, and surveys to accumulate larger sample sizes for Black and Caribbean populations. Expanding access to community-based intervention services for Black families, such as Fostering, Advocacy, Communication, Empowerment, and Support (FACES), can strengthen support for caregivers of individuals with ASD, improving resources and care (Pearson et al., 2024). Highlighting the challenges of the underrepresented Black and Caribbean populations and analysing the findings would assist in research to improve equality in services and care. In addition, a behaviour analyst should engage in self-assessments to improve cultural awareness. Applied behaviour analysts work with diverse populations and need to provide culturally responsive services (Beaulieu and Jimenez-Gomez, 2022).

Conclusion

Collectively, research, especially in Black and Caribbean populations, should be extended due to underrepresentation resulting in gaps in the literature, inconsistencies in findings in existing studies, delays in diagnosis, and systemic barriers. Given the prevalence of autism in Black and Caribbean populations, measures must be taken to further research to improve life outcomes and address the existing gaps within these communities. Gathering additional findings on females and diverse populations, including nonverbal cues, will decrease stigma, improve awareness, and provide more efficient access to care and resources. This will allow researchers, stakeholders, and policymakers to target challenges by developing new policies, programmes, and greater access to resources to improve the quality of life as young people transition into adulthood. Moreover, policies are encouraged to support both individuals with ASD and caregivers, helping them continue building skills and independence that will aid stability.

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