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Race, education affect mothers' perceptions of raising a child with autism spectrum disorder

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(Medical Xpress) -- As children with autism spectrum disorder transition into adolescence, how mothers perceive the impact of their child on their lives is influenced by ethnicity and education levels, a new University of Michigan study found.

Until now, few studies that examined the family impact of a child with autism spectrum disorder factored their diverse backgrounds during the transition to adolescence from childhood. Research shows that for some families mothers experience increased amounts of negative financial, social or emotional experiences during this period.

African-American mothers whose education included some college reported significantly lower levels of perceived negative impact in the study's two time periods when children were ages 9 and 14.

One possibility is that mothers with higher levels of education have greater understanding of the complexity of the disorder and difficulties their child may face, said Themba Carr, a post-doctoral research fellow in autism early intervention studies at the Center for Human Growth and Development.

"Mothers with higher education may also have higher aspirations for their child's achievements, and consequently, higher levels of disappointment in the limitations of their child," said Carr, the study's

lead author who collaborated with Catherine Lord, director of the new Institute for Brain Development at New York-Presbyterian Hospital, Weill Cornell Medical College and Columbia University Medical Center.

Cultural differences might also affect mothers' perception of negative impact. The tradition of strong social networks and higher levels of religiosity among some African-American communities may be protective. Carr said African-American women in the study "may perceive caring for a child with autism as less of a burden and more of an accepted familial obligation."

The study used data involving children who had an early diagnosis of autism at age 2. Researchers gathered information from mothers through face-to-face assessments and interviews (when their children were 9) and through questionnaires and phone interviews (when their children were 14). The questionnaire asked about how the child's symptoms affect the family dynamics, such as finances, relationships and activities.

One of the striking findings that researchers noted compared the number of hours of treatment that African-American and white children received since being diagnosed at age 2. By age 9, white children received on average 1,856 more hours of individual therapy than African-American children, which increased to 1,958 more hours by age 14.

"It could be that families that perceive children as a greater burden advocate more for services, or that having fought for services, some families are more aware of their children's negative impact on their lives," Carr said.

It may also be that parents perceive lower levels of negative impact of caring for their child do not feel as great a need to access services, she said.

"It is our hope that the findings of this research contribute to our understanding of the experiences of families of children with ASD from diverse backgrounds and help to promote accessibility to treatment services," she said.

More information: The findings appear in the current issue of *Autism*: aut.sagepub.com

Provided by University of Michigan

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