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Late autism diagnosis in males linked to mental distress

Late diagnosis of autism has significant negative ramifications. That's according to the latest study by the University of Cape Town's (UCT) researchers. The findings show that late diagnosis negatively impacts individuals' psychological well-being due to factors such as social isolation, bullying and psychological distress caused by a lack of understanding of autism-related difficulties.

The study, published in the international peer-reviewed journal, *Current Psychology*, explored the first-hand experiences of ten adult males – 25 years and above – who were diagnosed with autism during adulthood. Through in-depth interviews, the researchers sought to explore and understand symptoms and challenges in childhood associated with autism that were missed or misdiagnosed, the ramifications, and the impact of receiving a diagnosis of autism in adulthood.

Autism is a pervasive neurodevelopmental disorder associated with atypical functioning and qualitative impairments in individuals across three major areas: social interaction, social communication, and restricted, repetitive behaviour.

The findings revealed that individuals are also impacted in that, without support services, they become restricted in their abilities to thrive as there is no support within families and schools to assist with scaffolding the environment to help individuals with autism better manage their challenges.

Dr Anastasia Maw, co-author of the study, said: "The clinical implication for these findings emphasizes the urgent need for teachers and mental health professionals to be trained to better screen, assess and diagnose milder presentations of autism as early as possible. Parents need to be provided psychoeducation to raise awareness for the disorder and to access available support services."

The global prevalence rate of autism has increased significantly in the past years. The initial estimates were as low as 5 in 10 000 children and more recent studies indicate that 1 in 160 children globally have autism.

Commenting on the findings, Maw shared: "We found that indicators of autism were evident during early and later childhood. However, these symptoms were either overlooked or normalized by parents and teachers or understood as due to a psychiatric disorder other than autism by mental health practitioners. This had a significant impact on the overall life

experiences and outcomes for the participants in this study, as they were forced to navigate through their lives without an understanding of their difficulties.

As these individuals progressed through life, they encountered numerous challenges and adopted various strategies to cope with some of their autism-related difficulties. Some of these coping mechanisms were maladaptive, while those that were considered as being adaptive, had unintended negative consequences.”

The study also found that receiving a late diagnosis affected the participants’ ability to attain a sense of normalcy, as their autism-related challenges affected their ability to progress academically and attain and retain employment.

“We found that ineffective strategies of managing participants’ autism-related challenges were used by caregivers and participants. Participants in this study described using maladaptive coping strategies such as masking, substance use and withdrawn behaviour, while caregivers employed strategies such as discipline as an attempt to manage challenging behaviour,” said Maw.

According to Maw, the phenomenon of masking social difficulties was described by participants as a deliberate attempt to learn and use neurotypical social skills to fit in.

“Several participants described engaging in masking at an unconscious level through observing the behaviours of others and mimicking them without being aware of it. Masking had positive outcomes in that it provided a way for participants to manage their difficulties and navigate their way through the world. However, masking also resulted in negative outcomes, because the effort required to hide challenges and differences resulted in exhaustion and an increased sense of isolation and distress at not being able to fit in,” she said.

She noted that the participants expressed that receiving a diagnosis had significant positive benefits for them, as a better understanding of their challenges allowed them to develop tools that will help them move forward.

“They expressed how they now understand the underlying cause for their difficulties in forming relationships and other challenges they had, but most importantly, how gaining this understanding has enabled them to be more accepting of who they are.”

The participants whose families and friends were accepting, and supportive following disclosure of the diagnosis resulted in participants being more accepting of their diagnosis and finding adaptive ways to manage some of their challenges, including disclosure in the workplace, which then allowed for requests for accommodations.

“The participants who chose not to disclose their diagnosis to their employers due to various reasons, such as the possibility of being labelled and the stigma attached to conditions on the autism spectrum, did not express the same level of acceptance of their diagnosis as those who had disclosed and received support from their families and friends,” she said.

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