Finding out you're autistic in later life can be a positive experience, say researchers

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Receiving an autism diagnosis in your 20s, 30s, 40s, 50s or even 60s may seem daunting, but a new study from psychologists in Bath and London finds that the link between the age at which someone gets diagnosed has
little bearing on their quality of life.

So-called "late diagnosis" for autism has hit the headlines recently thanks to autism campaigner Christine McGuiness. Whereas autism is usually diagnosed in childhood, it is increasingly being diagnosed in adults and especially among women.

Parents often wonder if their child finding out they are autistic earlier or later will have an impact on their lives in the long term. While many people who discover they are autistic as adults wonder what life would have been like if they had found out earlier.

Against this backdrop the new study—carried out by researchers at the University of Bath and King's College London—is the first to examine whether the age at which one becomes aware of being autistic is linked to their quality of life, after accounting for other crucial factors such as household income.

The researchers asked 300 autistic adults to report the age at which they first learned they were autistic, as well as detailed information about their socio-demographic background such as current age, sex, ethnicity, relationship status, living status, education level, employment status, household income, and the presence of additional mental health conditions. Participants' level of autistic personality traits was also measured.

Participants then completed questions on different aspects of their quality of life—including physical, psychological, social, environmental aspects. For example, questions such as "To what extent do you feel your life to be meaningful?" and "How satisfied are you with the support you get from your friends?".

The results, published in the journal Autism, found that the relationship
between the age at which one becomes aware of being autistic and the different areas of quality of life was not statistically linked after considering other factors. In fact, other factors were more strongly linked to quality of life: Autistic women reported a better quality of life than autistic men, and people who had additional mental health conditions (e.g., anxiety) reported a lower quality of life.

Senior Research Fellow at the University of Bath and Lecturer in Psychology at King's College London, Dr. Lucy Livingston, said, "More and more people are finding out they are autistic for the first time as an adult, which can be a life-changing realization. Because we know that many autistic people experience a very poor quality of life and well-being, this begs the question whether finding out you are autistic earlier in life improves outcomes.

"Our findings did not suggest this. For some people, finding out they are autistic sooner rather than later was linked to a better quality of life. For others, finding out later was better. Overall, there was no overall link between the age they found out and their quality of life.

"There could be many reasons for this. Getting an autism diagnosis does not always lead to any meaningful additional support, so it could be that autistic people who learn they are autistic at an earlier age did not necessarily experience a benefit to their life quality. Equally, a late diagnosis in adulthood can be a positive experience, helping people to make sense of themselves, which may improve their self-reported quality of life. The take-away message is that the impact of an autism diagnosis on someone's quality of life is different for everyone. And there may be other, individual factors that are more important to focus on."

Lead Researcher at the University of Bath, Dr. Florence Leung, added, "Our findings revealed that having more autistic personality
characteristics—irrespective of when you learn you are autistic—was the strongest link to poor outcomes across all areas of quality of life. We are now following up on this finding to look more closely at how different autistic characteristics contribute to quality of life. This will be an important step towards establishing more tailored, more efficacious support for autistic people based on their specific autistic strengths and difficulties and self-evaluation of their quality of life.

"Additionally, being male and having additional mental health conditions was linked with poor quality of life. These observations highlight the importance of considering support strategies that are gender-specific to have a more targeted focus on improving autistic people's mental health, to improve their life outcomes. There has understandably been quite a lot of discussion on autism and mental health in females in recent years but, based on these findings, we should not overlook the needs to autistic males who might also be struggling."

Co-author and Associate Professor at the University of Bath, Dr. Punit Shah, said, "Our research more generally adds to a better understanding of neurodiversity across the lifespan. Autism, for a long time, was thought about as a childhood condition. Many still think this way. But people may not realize that most autistic people, in the UK for example, are now actually adults. With an aging society, this pattern will increase over the next few decades, so it is critically important that we conduct more detailed investigations into individual differences among autistic adults, as we have done. Such autism research in adults will thereby start to reveal the many different ways in which we can understand and support autistic people right throughout their lives, moving beyond a 'one size fits all' approach."

Provided by University of Bath

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