

‘I was exhausted trying to figure it out’: The experiences of females receiving an autism diagnosis in middle to late adulthood

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Autism Spectrum Condition (ASC) diagnoses often occur later for females than for males. So, many females’ needs are not understood until later in life. This means that they cannot be supported in the most helpful ways. There is little research asking autistic females about their experiences. Therefore, we conducted a research project about this. Our research investigated the experiences of 11 females diagnosed with ASC when they were aged 40 years or older. The answers to the interview questions were analysed using a research method called Interpretative Phenomenological Analysis. This research method allows researchers to gather detailed information about individuals and their specific life experiences in relation to a certain topic or event. The analysis involves using psychological understandings to interpret what individuals have said and to summarise this in a helpful way for their stories to be heard.

Our results showed that ASC seemed to be misunderstood by several people. Before they were diagnosed, our group of females had used strategies to try to ‘fit in’ with others. Many had been previously given other diagnoses (e.g., mental health conditions such as Borderline Personality Disorder and complex trauma) that were incorrect. This made life very difficult and many of the females in this research experienced significant difficulties with their mental health. After the diagnosis of ASC, the females described experiences of grief and sadness as they thought about how difficult their life had been before. Getting used to their new diagnosis was seen both positively and negatively by other people. After the diagnosis, many of the females experienced positive changes in their relationships and they began to accept themselves for who they were, rather than trying to change to ‘fit in’. Some of the females also felt that they had increased control over their lives. The research suggests that a diagnosis in earlier life could have prevented these females having such difficult life experiences. We further suggest that mental health services and schools require training to better understand ASC in females.