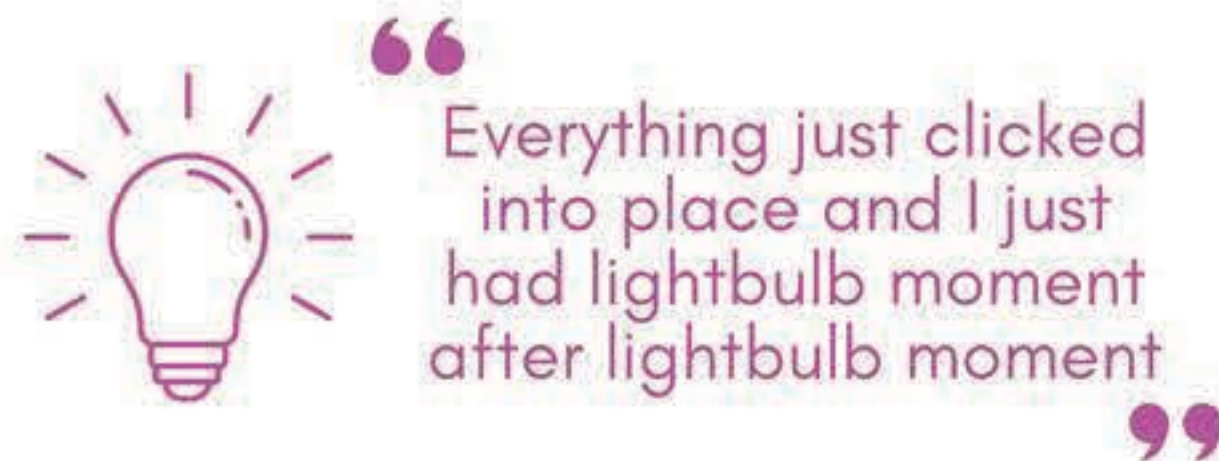


“Peas in a pod”: Oral history reflections on Autistic identity in family and community by late-diagnosed adults

Rozanna Lilley^{1,2}, Wenn Lawson^{1,2}, Gabrielle Hall^{1,2}, Joanne Mahony^{1,2}, Samuel Arnold^{2,3}, Julian Trollor^{2,3}, Michael Yudell⁴ and Elizabeth Pellicano^{1,2}

¹Macquarie School of Education, Macquarie University; ²Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane; ³Department of Developmental Disability & Neuropsychiatry, University of New South Wales; ⁴Dornsife School of Public Health, Drexel University, USA



Project aim

We sought to document the experiences of Australian autistic adults who grew up in an era when autism was not well known.

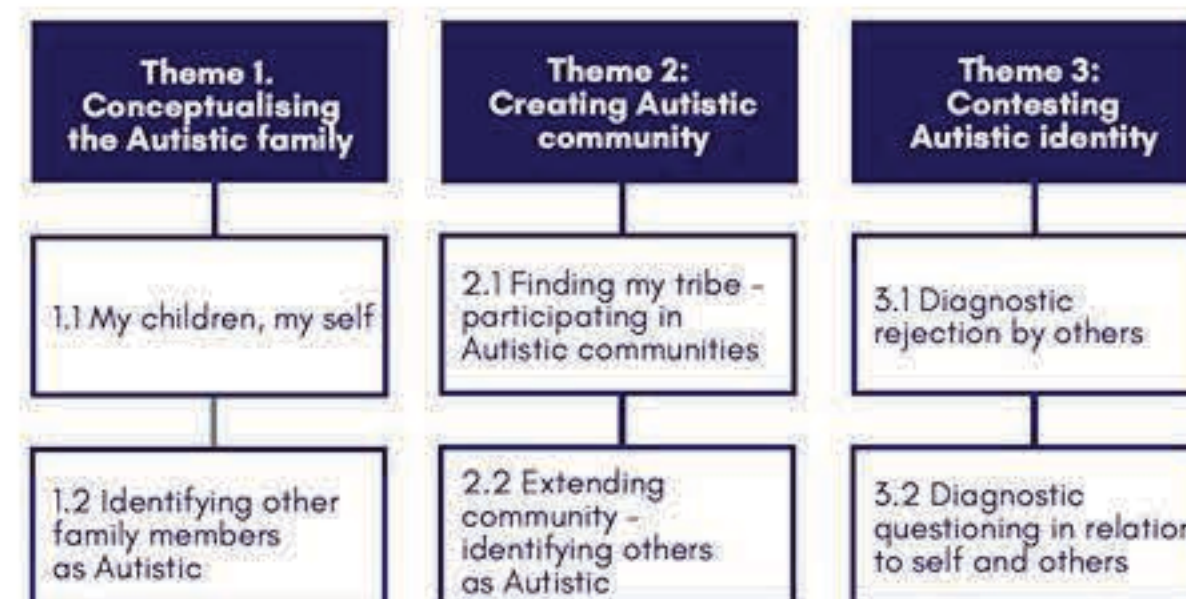
Using both qualitative oral history and participatory methods, this study offers key insights into Autistic perceptions of the self and shared identity.

Methods

Twenty-eight participants were recruited. All were born before 1975 and received a clinical autism diagnosis after the age of 35, at, on average, 49 years. All interviews (M length = 129 minutes) were conducted by Autistic researchers, transcribed and then thematically analysed by a team of Autistic and non-autistic researchers using the six-step process outlined by Braun and Clarke (2006, 2019).

Results

We identified three themes in these oral history reflections relating to shared Autistic identity.



1. Conceptualising the Autistic family

Interviewees reflected on both immediate and extended family, highlighting how they identified with their children diagnosed with autism. They also spoke about retrospectively identifying other family members as Autistic.



“We’re like peas in a pod”

2. Creating Autistic community

Participants described a sense of shared identity in Autistic communities, online and face-to-face. They also stated that they had developed an ability to identify other people as Autistic, extending the idea of community to potentially encompass others not formally identified by diagnostic professionals.

“I can quite often spot who the other autistics are”

“I’d found my tribe”

3. Contesting Autistic identity

Interviewees spoke about the way other people, including family members and professionals, sometimes rejected the Autistic identity of interviewees. This generally caused considerable distress. Some interviewees also said that there have been times when they have questioned their own identity as Autistic.

“I got diagnosed at 51. He [father] just said that is rubbish”

“Maybe I’m not autistic enough”

Conclusions

These themes reflect the complexity of all processes of identity construction, including membership in diagnostic categories.

In identifying family members and others as Autistic, our participants asserted the value of their own embodied understanding of autism.

Their accounts of finding a ‘home’ in Autistic communities extend the idea of family, creating a safe space in which to belong.

Reports of questioning Autistic identity provide insights into identity formation as processual and, on occasion, contested. Overall, these ideas about identity and community challenge some orthodox understandings of autism.

Objectives

Late-diagnosed autistic adults offer a unique resource for understanding lived experiences of autism over time.

In this study, we sought to understand autistic perceptions of the self and ideas about shared identity through listening to and learning from their autobiographical accounts.

For more information

Rozanna Lilley | Phone: +61 (0)412249961 | Email: rozanna.lilley@mq.edu.au

autismcrc.com.au
[@autismcrc](https://twitter.com/autismcrc)