



AutismCRC

Investigating autistic burnout (#AutBurnout)

EXECUTIVE SUMMARY

Dr Samuel Arnold

Julianne Higgins

Dr Janelle Weise

Aishani Desai

Prof. Liz Pellicano

Prof. Julian Trollor

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MACQUARIE
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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

1. Executive summary

Although reported on social media by autistic people for some time, there has been little recognition of autistic burnout in the academic literature. Autistic burnout has been described as a debilitating condition negatively impacting functioning, even leading to suicidal ideation. Autistic adults have linked autistic burnout to the stress of masking or camouflaging, and living in an unaccommodating neurotypical world. This project sought to define autistic burnout, deepen understanding and create awareness of this syndrome within the research and autism communities. No scientific literature on autistic burnout existed at the time the project commenced.

In Phase 1, we defined autistic burnout using Grounded Delphi Method. Autistic adults were positioned as experts by lived experience of autistic burnout ($n=23$). They co-produced a definition of autistic burnout intended for clinicians and the autistic and autism communities. Qualitative data gave a thick description (Geertz, 2017) of the autistic burnout experience, that is, a description accessible to those outside of the autistic community. A conceptual framework was developed from the open-ended round 1 survey. By the round 3 survey there was a high level of agreement with the draft definition. Autistic burnout was defined as a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression and non-autistic burnout (Higgins et al., 2021).

In Phase 2, we sought to validate emerging definitions of autistic burnout, with definitions recently published by Raymaker et al. (2020) in addition to our published definition arising from Phase 1. We aimed to explore the validity of these definitions and determine factors associated with more severe autistic burnout. Using a co-produced mixed-methods online survey, 141 autistic adults with self-identified experience of autistic burnout endorsed characteristics described by Higgins et al. (2021). No consensus could be reached on criteria regarding the duration of autistic burnout. We also trialled the pre-publication burnout measure developed by Raymaker et al. (2020), which appeared to have poor specificity. We found that autistic burnout appears to be associated with camouflaging and depression. Perspectival incognizance, that is, an inability to be aware of and understand another's personal existential experience of life akin to Milton's (2012) double empathy problem, was associated with onset, recovery and ineffectiveness of non-autistic clinicians.

Further work is needed to differentiate autistic burnout from other conditions, with complex relationships to depression and numerous reports of misdiagnosis. Clinicians need better understanding of the accompanying complexity to be considered in treatment planning. Research is also needed to develop and validate measures and screening tools to assist clinicians and researchers to understand this syndrome.

Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



AutismCRC

Autism CRC

The University of Queensland
Long Pocket Precinct
Level 3, Foxtail Building
80 Meiers Road
Indooroopilly Qld 4068
T +61 7 3377 0600
E info@autismcrc.com.au
W autismcrc.com.au



@autismcrc



Australian Government
Department of Industry, Science,
Energy and Resources

AusIndustry
Cooperative Research
Centres Program