

Title: Confirming the nature of autistic burnout

Running head: Confirming autistic burnout

Authorship

Samuel R. C. Arnold^{1,2*}, Julianne M. Higgins^{1,2%}, Janelle Weise¹, Aishani Desai³, Elizabeth Pellicano^{4,2}, and Julian N. Trollor^{1,2}

[%]Joint first author

^{*}Corresponding author

¹Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW, Sydney, New South Wales, Australia;

²Cooperative Research Centre for Living with Autism (Autism CRC), Long Pocket, Brisbane, Queensland, Australia;

³Department of Psychology, Macquarie University, Sydney, New South Wales, Australia

⁴Macquarie School of Education, Macquarie University, 29 Wally's Walk, Sydney, New South Wales, Australia.

Corresponding Author:

Samuel R. C. Arnold, Department of Developmental Disability Neuropsychiatry, University of New South Wales, 30 Botany Street, Randwick, NSW, 2031, Australia.

Email: Samuel.arnold@unsw.edu.au

This is the accepted version of the following article:

Arnold, S. R. C., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N.

(2023). Confirming the nature of autistic burnout. *Autism*. OnlineFirst.

<https://doi.org/10.1177/13623613221147410>

which has been formally published in *Autism*. This accepted version may be shared in accordance with the SAGE Author Archiving and Re-Use Guidelines.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program.

Acknowledgements

We would like to thank Yunhe Huang for her support in data analysis and discussing concepts.

Lay Summary

Autistic burnout is something autistic people have been talking about for a while (see #AutBurnout and #AutisticBurnout on social media). Recently, researchers published two different definitions of autistic burnout. We wanted to test these definitions. We wanted to confirm the duration and frequency of autistic burnout. That is, how long and how often do people get autistic burnout? We surveyed 141 autistic adults who had autistic burnout. We used descriptive statistics, content analysis and reflexive thematic analysis to analyse the survey responses. Autistic adults strongly agreed with the definition published by Higgins et al. (2021). How long and how often people get autistic burnout wasn't clear. Participants told us they have both short and long episodes. Participants told us that autistic burnout leads to exhaustion. They needed to withdraw from being with other people. They needed to stay away from autism unfriendly places. Many had been misdiagnosed as having depression, anxiety, bipolar disorder, borderline personality disorder or other conditions. We need increased awareness of autistic burnout. Autistic people need more help. More research is needed, we need to have bigger studies to understand autistic burnout.

Title: Confirming the nature of autistic burnout

Abstract

Autistic burnout is an experience commonly described by autistic people (#AutBurnout and #AutisticBurnout on social media). Recently, two definitions of this syndrome have been published. Both describe debilitating exhaustion with onset related to various stressors including masking, though several differences exist, such as the characteristic of interpersonal withdrawal. We sought to explore the content validity of these definitions including duration and frequency criteria, using descriptive statistics, content analysis and reflexive thematic analysis. A co-produced survey of 141 autistic adults with experience of autistic burnout showed strong endorsement of the Higgins et al. (2021) definition, where exhaustion and interpersonal withdrawal occur alongside reduced functioning, executive functioning difficulties, and increased manifestation of autistic traits. Duration and frequency criteria were unresolved, with qualitative data highlighting varying (both acute and chronic) experiences. Autistic burnout is frequently misdiagnosed as depression, anxiety, bipolar disorder, borderline personality disorder or other conditions. Work is needed to increase community and clinician awareness, as well as initiatives to improve unaccommodating neurotypical environments. More research and validation are needed in larger samples not restricted to autistic adults who have experienced autistic burnout in order to determine prevalence and risk factors as well as duration and frequency.

Introduction

The high incidence of mental illness in autistic adults is well established (Hollocks et al., 2019). Recent work links autistic people's attempts to camouflage or mask their autistic characteristics with considerable risk of mental illness (Bradley et al., 2021) and suicide (Cassidy et al., 2018). The effort of ongoing masking (aka. Camouflaging; adaptive morphing; i.e., behaviour to conceal one's autistic traits within social interactions (Hull et al., 2017; Lawson, 2020)) and the debilitating exhaustion experienced by autistic adults from the stress of living in an unaccommodating neurotypical world has been called 'Autistic burnout' by those who have experienced it (e.g. Endow, 2017; Rose, 2018). Although the causes, experience and impact of autistic burnout have been discussed across social media and other platforms, there has been limited research thus far to explore the syndrome and its implications. The absence of such research, including the development of a consensus definition and related measurement tools, makes it challenging to design appropriate supports and accommodations for prevention and recovery.

Drawing on social media and interview data using a community-based participatory research approach, Raymaker et al. (2020) were the first to define autistic burnout as:

... a syndrome conceptualized as resulting from chronic stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus.

They further distinguished autistic burnout from clinical depression and occupational burnout, suggesting it is distinct in its aetiology and presentation (Raymaker et al., 2020). In particular, reports of sleep problems and anhedonia, which are common characteristic of depression, were absent from their data. Their study highlighted the importance of validating

the autistic community's experiences with clinical evidence, and of educating practitioners and the broader community about the potential causes and impact of autistic burnout.

The second study on autistic burnout also suggested that autistic burnout is distinct from clinical depression (Higgins et al., 2021). This study, co-led by an autistic adult with lived experience of autistic burnout, developed a consensus definition of autistic burnout using Grounded Delphi Method (GDM; Howard, 2018). GDM combines grounded-theory methods, useful for theory building, with Delphi, useful for expert consensus building in areas with little established literature. Experts by experiences defined autistic burnout as:

a severely debilitating condition with onset preceded by fatigue from camouflaging or masking autistic traits, interpersonal interactions, an overload of cognitive input, a sensory environment unaccommodating to autistic sensitivities and/or other additional stressors or change

with primary criteria of “*1. Significant mental and physical exhaustion*” and “*2. Interpersonal withdrawal*”, alongside reduced functioning, difficulties with executive function and / or increased intensity of autistic traits.

There are some inconsistencies in the two definitions published thus far. For example, Higgins et al. (2021) identified masking or camouflaging as a key element contributing to the onset of autistic burnout, whereas Raymaker et al. (2020) described this as a possible life stressor that could lead to autistic burnout along with a combination of other factors. Another major difference was the role of withdrawal as explained in the manifestation of burnout. Raymaker et al. (2020) described withdrawal as a mechanism of recovery during an autistic burnout episode, whereas Higgins et al. (2021) found that autistic experts reported withdrawal as a symptom of the burnout episode. Raymaker et al. (2020) suggested a 3+ month duration, whereas Higgins et al. (2021) could not identify a specific duration criteria

from their data. Similarly, recent work from Phung et al. (2021) interviewing eight children and youth could not distinguish between autistic burnout and shutdown, with children reporting on “exhaustion” and “freezing”, though they cautioned this may be related to a reduced vocabulary compared to adults.

The aims of the current study were twofold. Specifically, we sought to (1) explore the content validity of these two emerging definitions; and (2) quantify the duration, frequency and intensity of autistic burnout. To address these aims, we conducted an online mixed methods survey combining items based on emerging definitions with standardized measures. This manuscript reports on a portion of the survey findings focused on items exploring content validity.

Methods

Participants

A volunteer sample of participants were recruited through advertisement on social media, the Australian Longitudinal Study of Autism in Adulthood (Arnold et al., 2019) newsletter, autism organisation websites and newsletters. All participants were required to have an independent clinical diagnosis of autism, and to have experienced a self-identified episode of autistic burnout. A total of 141 participants provided useable data to the anonymous survey, with higher numbers of females (64%, $n=88$) and participants reporting another gender (20%, $n=28$) than males (16%, $n=22$; $n=3$ missing). Mean age was 40.2 years ($SD = 10.8$, range: 20.3 - 71.0; $n=8$ missing). Two participants (1%) scored 64 and 65 on the Autism Spectrum Quotient-28 (AQ-28), below the >65 cut-off which has a sensitivity of 97% (Hoekstra et al., 2011), but were not excluded from the analysis.

Approximately half of the sample was employed, the majority completed high school to year 10 or higher and had a bachelor’s degree or higher (see Table 1). Most were

diagnosed recently in adulthood (M years since diagnosis = 3.4 years, $SD = 5.3$, range = 0 – 27; M age at diagnosis = 36.9 years, $SD = 12.4$, range = 3.4 – 67.1). Table 1 shows further demographics and background information.

Table 1

Demographics and mental health conditions (N=141)

Characteristic	n (%)		
Currently employed ($n=5$ missing)	77 (57)		
Education			
Completed Year 10 or higher ($n=5$ missing)	130 (96)		
Bachelors Degree or higher ($n=10$ missing)	88 (67)		
Marital Status ($n=3$ missing)			
Single / Divorced	44 (32)		
Married / de-facto	60 (44)		
Separated	14 (10)		
Widowed	6 (4)		
Other / Don't know	14 (10)		
Living situation			
Alone	38 (27)		
Couple	61 (43)		
With parents / relatives	24 (17)		
With others	10 (7)		
..Other	8 (6)		
Born in Australia ($n=6$ missing)	118 (87)		
Ethnicity Caucasian ($n=5$ missing)	115 (85)		
Mental Health Conditions ($n=3$ missing)		Current diagnosis	Previous diagnosis
			Currently receiving treatment
Anxiety	100 (72)	24 (18)	76 (55)
Depression	66 (48)	53 (38)	60 (43)
Attention Deficit/ Hyperactivity Disorder	57 (41)	5 (4)	37 (27)
Social anxiety	56 (41)	23 (17)	40 (29)
Post-Traumatic Stress Disorder	39 (28)	20 (14)	22 (16)
Panic disorder	17 (12)	25 (18)	18 (13)
Eating disorder	13 (9)	11 (8)	5 (4)
Obsessive Compulsive Disorder	10 (7)	11 (8)	10 (7)
Bipolar disorder	8 (6)	18 (13)	7 (5)
Personality disorder	5 (4)	13 (9)	3 (2)
Pathological grief	5 (4)	4 (3)	0 (0)
Substance abuse	1 (1)	15 (11)	0 (0)
Tic disorders	1 (1)	2 (1)	0 (0)
Schizophrenia	0 (0)	3 (2)	0 (0)
Other mental health disorder*	12 (9)	0 (0)	9 (7)

*Other conditions reported more than once included Premenstrual Dysphoric Disorder and Dissociative Identity Disorder

Survey Tool

Autistic Burnout Survey. The research team, co-led by autistic researcher JH, developed a series of items to investigate the experience, onset and recovery from autistic burnout (see Supplementary Materials). Items addressed specific elements referred to in definitions, such as withdrawal, a mismatch of ability and demands, executive functioning and amplified autistic traits in order to test endorsement of the proposed characteristics. All quantitative survey items were scored on 7-point Likert agreement scale (1 strongly agree to 7 strongly disagree) with an additional ‘not applicable’ option, and each question block was followed by open-ended items probing for additional detail or missing concept coverage. As we were not targeting people with intellectual disability, we chose to use this response format. We used plain language (Weaver et al., 2021) and a range of response options where possible (Nicolaidis et al., 2020) Items were informed directly by Higgins et al. (2021) and Raymaker et al.’s (2020) definitions. JH, SA and AD developed items, which were then reviewed by all co-authors. We provided further analysis of participants’ responses to quantitative survey sections in a separate paper ([blinded for review]).

Autism Screening. We used the Autism Quotient-28 (AQ-28; Hoekstra et al., 2011) to determine whether participants met cut-off for autism. The AQ-28 is an abridged version of the widely used 50-item AQ tool (Baron-Cohen et al., 2001), originally developed to identify autistic traits in adults of at least average intelligence. It uses a 4-point Likert scale (1 Definitely agree; 2 Slightly agree; 3 Slightly disagree; 4 Definitely disagree). Using a cut-off of >65 demonstrates high sensitivity (97%) and specificity (82%) for distinguishing between autistic and non-autistic participants (Hoekstra et al., 2011).

Data Analysis

Data were analysed using a combination of content analysis, descriptive statistics, and reflexive thematic analysis, as different methodological approaches were suited to different item types within the survey and the different research questions. Specifically, content analysis was most suited to understanding frequency of misdiagnosis, descriptive statistics most suited to Likert scale items, and reflexive thematic analysis most suited to open ended question probing for new content that might not have already been identified in Likert scale items that were based on the existing definitions of autistic burnout. We used this approach to maintain the centrality of autistic voice wherever possible and represent the responses of the autistic participants authentically. Despite using multiple methodologies results are presented according to the topic areas and flow of the survey to create a narrative for the reader.

All quantitative data were analysed using Stata 15. Basic descriptive statistics were calculated with survey item responses presented ordered by highest mean scores.

Qualitative data analysis was led by autistic peer-researcher JH, and applied to all open-ended questions, excluding content analysis of the question probing misdiagnosis which was completed by SA, a registered psychologist. Having an autistic peer researcher lead the thematic analysis in this exploratory research was critical. JH used an inductive approach to reflexive thematic analysis (Braun & Clarke, 2019) from a contextualist perspective (Madill et al., 2010) where the subjectivity of her lived experience of autistic burnout was key to the analytic process, identifying meaning at latent and semantic levels. Given known difficulties in understanding lived experiences (Milton, 2012) between autistic and non-autistic people, exploratory research of autistic experiences required an autistic person who can empathize with and synthesize the specific lived experience of autistic burnout. Insider research is critical in this context to prevent misinterpretation. The accessibility and flexibility of reflexive thematic analysis (Byrne, 2022) made it particularly suited to the study, enabling

the autistic researcher to work with the data section by section in a manageable format. To avoid repetition, we focused on themes not already evident in quantitative responses, as open-ended questions were posed in the form of “do you have any other comments?”.

JH reviewed responses one question at a time, applied codes, re-read responses, identified and summarised themes in discussion with SA. Responses to the two open-ended questions regarding recovery were analysed together. We also identified commonalities in themes across different survey sections. JH and SA met regularly to discuss themes, the process of analysis and presentation of the results. All authors reviewed final themes arising and presentation of results, with some themes renamed during the review process.

Handwritten notes, MS Word and Excel were used for analysis of most items, with NVivo used for processing the two recovery-related items. See Supplementary Materials for a table of additional quotes that was developed to support the selection of themes and allow the reader deeper appreciation of participant responses.

We conducted content analysis of misdiagnosis responses as a manifest analysis following Bengtsson (2016). The inter-rater reliability check of the content analysis was completed by SA and a research assistant with an undergraduate degree in psychology. Initially there was 80.2% exact agreement on categorisation of the response, with disagreement primarily related to the definition and additional rating of co-existing conditions, and 90% agreement on the named misdiagnoses. Following discussion and refinement of the coding framework in joint review 100% agreement on response and related diagnosis was reached.

Community Involvement

This project was co-led with autistic peer researcher JH, who has lived experience of autistic burnout. In addition to data analysis, JH co-produced the research questions, funding application, survey tool and was involved in data analysis, leading qualitative data analysis, reviewing all interpretations of findings and co-authoring outputs. JH's major impact on the conduct and outcomes of the study are acknowledged with her position as joint first author.

Results

In addition to quantitative findings, thematic analysis across sections of the survey identified numerous themes, as summarised in Table 2. *Many participants provided rich responses to open-ended items.* Additional to data presented in text, further quotes supporting these themes are reported in Supplementary Materials. Following the overview of themes in Table 2, results are presented by each topic area of the survey, interspersing thematic and statistical results.

Table 2: Summary of themes across sections

Section / Theme
Exploring a mismatch between expectations and ability
(1) Ableism
(2) Perspective disconnect
(3) Lack of consideration and lack of support
Characteristics of onset
(1) Physical signs of onset
(2) Difficulties in recognition
(3) Chronic and acute episodes
(4) Attempts to avoid full burnout
(5) Intense engagement
(6) Unaccommodating environments
(6a) Community / interpersonal
(6b) Socio-political structures and systems
(6c) Workplace

Characteristics of recovery, support and consequences

- (1) Seeking assistance
 - (1a) Useful therapies
 - (1b) Lack of understanding and support
 - (1c) Unaccommodating neurotypical world
- (2) What is needed for recovery
 - (2a) Protective
 - (2b) Restorative
 - (2c) Animals, nature, water and low sensory environments
 - (2d) Space and time
 - (2e) Incomplete

Frequency and duration of autistic burnout

- (1) getting older
 - (2) increased life demands
 - (3) autism diagnosis
 - (4) awareness and understanding
 - (5) self-management
-

Characteristics of autistic burnout

Exhaustion and social withdrawal were the most strongly endorsed characteristics regarding the participants' most recent autistic burnout experience (see Table 3). Most items had high endorsement, items relating to meltdown were the least endorsed.

Table 3*Autistic Burnout Experience Items Ordered by Highest Mean Agreement*

Survey Item	Obs.	Mean agreement	SD	Min^a	Max
1. I felt extremely tired or worn out.	140	1.15	.45	1	3
4. I was mentally exhausted.	141	1.20	.51	1	4
7. I withdrew from social situations.	139	1.24	.56	1	3

8. I had difficulties doing my usual work as well as I typically do.	135	1.30	.67	1	5
5. I felt overwhelmed by my environment.	141	1.34	.83	1	6
12. I found it more difficult to relate socially to people.	141	1.42	.81	1	6
3. I was physically exhausted during the day.	140	1.47	.76	1	4
27. I found some of the following more distressing than usual: Sudden or loud noises, bright or flickering lights ...	141	1.48	1.00	1	7
25. Communicating with others was more difficult than usual.	141	1.48	1.00	1	7
10. I had difficulties with my school or academic tasks.	90	1.51	.78	1	4
6. I withdrew from family members or other people I live with.	139	1.58	.94	1	5
2. I did not have the energy to carry out daily activities.	141	1.60	.88	1	5
23. I had a hard time planning my day ...	140	1.65	1.04	1	7
33. My other mental health problems got worse.	133	1.67	1.06	1	7
20. I found that I took longer to complete tasks.	140	1.69	1.14	1	7
22. I was easily distracted.	139	1.76	1.14	1	7
36. I was overwhelmed with emotions.	141	1.85	1.2	1	7
21. During conversations, I took longer to respond to questions.	139	1.88	1.17	1	7
13. I lost interest in doing activities that I usually enjoy.	140	1.89	1.41	1	7
34. I was more self-critical.	140	1.90	1.34	1	7
32. My physical health conditions got worse.	134	1.99	1.39	1	7

9. I was unable to do my usual work.	137	1.99	1.33	1	7
14. I was unable to do activities that I usually enjoy.	141	2.00	1.36	1	7
28. I found myself avoiding ... environments that I would typically enjoy (For example: Christmas, weddings).	133	2.02	1.34	1	7
18. I had difficulty remembering instructions given to me.	140	2.04	1.33	1	7
15. I experienced some time of confusion.	141	2.07	1.29	1	7
45. I felt very restless and distressed.	140	2.13	1.49	1	7
29. My repetitive behaviours / stimming increased ...	138	2.17	1.34	1	6
24. I had difficulty maintaining my usual self-care routines....	141	2.17	1.69	1	7
40. I felt intense distress.	141	2.19	1.59	1	7
30. I had an intense need for 'sameness' in my daily activities...	141	2.27	1.40	1	6
31. I lost my ability to hide that I was autistic....	138	2.38	1.54	1	7
11. I was unable to do any school or academic tasks.	90	2.41	1.61	1	7
16. I experienced gaps in my memory.	139	2.55	1.79	1	7
17. I had difficulty remembering specific events.	140	2.59	1.72	1	7
37. I felt emotionally numb.	139	2.67	1.82	1	7
35. I would talk to myself.	139	3.01	1.79	1	7
26. I was unable to communicate with others.	141	3.01	1.63	1	7
43. I would have angry outbursts.	140	3.42	1.91	1	7
41. I would pace or walk back and forth a lot.	135	3.48	2.09	1	7
39. I felt unbearable internal pain.	138	3.64	2.07	1	7

48. I thought a lot about killing myself.	136	3.95	2.21	1	7
19. At times, I temporarily forgot things about myself including who I am.	138	4.12	1.95	1	7
44. I would hurt myself (For example: bang or hit my head).	135	4.30	2.18	1	7
46. My body moved quickly and I could not stop it.	137	4.34	2.12	1	7
38. I would yell uncontrollably.	135	4.41	2.18	1	7
47. I started to self-harm (For example: cutting myself).	131	5.05	2.06	1	7
42. I became physically aggressive.	136	5.30	1.84	1	7

Note: ^aScored 1 strongly agree to 7 strongly disagree

Exploring a mismatch between expectations and ability

One key element of the Raymaker et al. (2020) definition is reference to a mismatch between expectation and (in)ability. Probing the cause on this mismatch was not suggestive of inability, from the response options provided, 82% ($n=116$) of participants endorsed “being exhausted from too many things that drain my energy”, 80% ($n=113$) endorsed “Too many stressors that add up over time”, 73% ($n=103$) endorsed “Unaccommodating environments (e.g. sensory overloading, socially difficult, physically inaccessible)”, 68% ($n=96$) endorsed “Difficulty in obtaining relief from these stressors” and 62% ($n=87$) endorsed “Difficulty communicating with neurotypical people”.

Participants who responded to ‘Other reason’ (20%; $n=28$) provided data that reinforced the provided response options, though added additional context with three themes identified from thematic analysis. At systemic and community levels there was evidence of themes of unwitting (1) *ableism and lack of support*: “overly optimistic people not understanding /relating to my needs and putting on pressure to conform to their desires”; and

a (2) *perspective disconnect*, where the neurotypical person’s existential difference and disconnect impedes the awareness and understanding of another’s neurodivergent lived experience: “Lack of support about how I interact with people and bridging the gap between my autistic world and the neurotypical world of people who don't understand”. (3) *Lack of consideration and lack of support* of individual differences exists across all dimensions of life resulting in “not being eligible for help... self-care through NDIS¹ etc. or not being believed by NTs [neurotypicals]” including informal supports: “being excluded because of family members ignorance and lack of support.”

Characteristics of onset

Participants most strongly endorsed life stressors and sensory environment, which they felt made it more likely they will experience autistic burnout (see Table 4). Although all items were strongly endorsed on average, items relating to camouflaging were slightly lower in mean endorsement, potentially suggesting that although masking is a contributing factor. Overall life stress is more primary or common in causing autistic burnout.

Table 4

Autistic Burnout Onset Items Ordered by Highest Mean Agreement

Item	Obs.	Mean	SD	Min	Max
22. A build-up of life stressors	141	1.31	.80	1	6
2. Being overloaded by sensory and social information in my environment	141	1.36	.75	1	5
8. Having too many things that I have to think about and figure out	141	1.49	.97	1	6

¹ The National Disability Insurance Scheme (NDIS) is an Australian national program that provides funding for disability supports if the person meets criteria of a permanent impairment(s) that result in substantially reduced functional capacity.

5. Being in an environment with too much sensory stimuli ...	140	1.55	1.02	1	6
20. A mismatch between what I am expected to do, and what I can do	141	1.57	1.06	1	6
6. Having little control over my own life	141	1.64	1.11	1	7
12. Dealing with an unexpected life event ...	136	1.68	1.05	1	6
11. Expectations to act “normal” all the time	140	1.7	1.01	1	5
19. A mismatch between what I need to do, and what I can do	141	1.72	1.14	1	7
13. High pressure from my employment or education courses	125	1.75	1.20	1	6
10. Being misunderstood by non-autistic people I interact with	141	1.76	1.05	1	6
1. Having to hide my natural autistic personality and pretend to be non-autistic	141	1.83	1.18	1	6
7. My other physical or mental health conditions getting worse	136	1.97	1.17	1	7
15. Having to have big changes in my normal daily routine	141	2.06	1.39	1	6
18. Not having adequate time to spend on projects of personal interest	139	2.10	1.36	1	7
3. Having to follow the rules and conventions of a non-autistic world	141	2.11	1.35	1	7
4. Having to interact with non-autistic people too much	141	2.13	1.35	1	7
16. Having to change the primary activities I am focused on	141	2.16	1.45	1	7
21. A mismatch between what I am expected to do and my skills and ability	141	2.17	1.58	1	7
14. Having to play a difficult social role ...	120	2.21	1.38	1	7
17. The primary activities I am focused on being interrupted	141	2.25	1.47	1	7
9. Having difficulties understanding non-autistic people	140	2.31	1.38	1	7

Thematic analysis identified six themes and three subthemes covering the identification of onset, types of burnout and contexts. In identifying onset, (1) *Physical signs of onset* included: “I usually get lightheaded and have dizzy spells ... as well as hot flashes”, while for another “I notice I have difficulty saying words. I don’t forget them. They are in my

brain, but I can't get them to my mouth". Many described (2) *difficulties in recognition* of warning signs: "Onset was sudden, no warning or just creeping up", "It's difficult to know when normal life stressors will tip over to burnout." Some indicated difficulties resulting from interoception and alexithymia: "It (onset) can happen suddenly seemingly without warning because I cannot see the signs... I can't always feel hunger in my body until I feel nauseous. This is why I eat at routine times, but I don't always have control over my routines". The latter was also seen to impede recognition of autistic burnout: "Alexithymia is a part of my diagnosis which makes it very difficult to know when burnout is coming on". Some depend upon others to register impending burnout: "I cannot see it in myself and rely on those close to me to insist I implement strategies." Being aware of emotional responses may give an understanding but not necessarily avert the burnout experience: "don't usually realise I am experiencing autistic burnout until I recognise my emotional responses far exceed what they usually do... over a minor inconvenience e.g., misplacing a pen".

Our participants also described (3) *Chronic and acute episodes* of autistic burnout: "Other than this one very severe occasion, my less severe and more regular burnouts often occur... when socialising with neurotypical people." Participants described the "longitudinal aspect of burnout" with much shorter "incidental burnouts" leading to an "accumulated effect" from sensory overloads and social interactions that can occur on a daily basis. Several participants referred to experiencing both chronic and acute episodes: "autistic burnout in terms of ... several weeks /months of not being able to maintain employment or keep up the pretence of 'normal'... however, if you define burnout as spending the weekend in bed non-functional, that would be maybe 10 times per year". Some reported (4) *attempts to avoid full burnout*: "I have learnt to recognise it. I have strategies and supports. If I can get rest at the start, I can sometimes avoid it. Or, at least postpone it". Others weren't always supported to avoid burnout 'Normals' can't seem to accept the idea that 'I need time to myself' means that

I need time to myself”. Several responses were again suggestive of *perspective disconnect*, where the requests for accommodations by autistics are not recognised:

There are always signs and I try to tell people around me to stop doing things or leave me alone but they cannot seem to understand how urgent this is until I explode... no one takes notice when I ask nicely until it’s too late. It’s awful and frustrating and difficult.

Participants gave added description suggesting (5) *intense engagement* leading to overexertion driving onset: “comes after a state of high alert / focus”. Onset could occur in a variety of (6) *unaccommodating environments*, including the interpersonal: “trying to convince people it’s real. Especially family” with this participant relating both the (6a) *community / interpersonal* as well as (6b) *socio-political structures and systems* domains:

Despite my diagnosis I feel my ASD is not recognised or accepted by most people including family, the NDIS, and the mental health systems so trying to convince them I am experiencing autistic burnout on a regular basis seems well nigh impossible.

Others highlighted the stress of a neurotypical focused (6c) *workplace*:

Between expectations and what I can do is everything, if I could do things in a planned way at my pace I think I’d be fine... but when others are not organised and make last minute changes or expect me to quickly switch to give an update on a different activity than the one I’m currently working on it zaps my brain power and I lose my ability to do either that day usually.

Overall, participants’ autistic burnout experiences reflect upon our shared (6b) *social-political structures and systems*: “I wouldn’t burnout if there weren’t so many stressors: Why does the world have to be so competitive?”

Characteristics of recovery, support and consequences

Withdrawal and downtime were the most strongly endorsed items regarding things that “help me to recover”, with stimming the least strongly endorsed (see Table 5). In regard to support, or lack thereof, the most highly endorsed item was related to *perspective disconnect*, with expressed needs being minimised or dismissed. Friends, family and colleagues were all poorly rated in terms of being supportive. The highest endorsed consequences related to ongoing self-efficacy and fatigue concerns. Although suicide attempts were the lowest endorsed consequence, approximately half of respondents ($n=70$, 52%) showed some agreement towards suicidal ideation as a consequence of autistic burnout.

Table 5

Autistic Burnout Recovery, Support and Consequences Items Ordered by Highest Mean Agreement

Item	Obs.	Mean	SD	Min	Max
Recovery Items					
1. Withdrawing from interpersonal situations	140	1.59	1.00	1	6
3. Spending downtime on my personal interests	139	1.82	1.27	1	7
2. Ignoring externally imposed demands	140	2.22	1.71	1	7
5. Gradually returning to my everyday routines and activities	140	2.39	1.36	1	7
6. Gradually returning to engaging in activities	139	2.47	1.43	1	7
4. Spending time ‘stimming’	133	2.71	1.54	1	7
Support Items					
10. In the past, when I have asked for help, my problems have been dismissed or minimized.	139	2.144	1.386	1	7
8. I can access counselling or psychological therapy if I need it	141	2.624	1.641	1	7
1. I have not recovered the same level of ability and energy that I had prior ...	140	2.721	1.718	1	7
9. Counselling or psychological therapy is helpful to prevent or recover	138	3.312	1.94	1	7
7. External resources (such as disability services, child-care respite) are helpful to prevent or recover...	107	3.645	1.968	1	7

13. If I need to, I can take breaks during the day.	139	3.849	1.933	1	7
3. I find friends can be supportive and understanding in preventing or recovering ...	134	4.037	1.877	1	7
5. I have sufficient access to social support (such as family, friends, or colleagues)	138	4.21	2.066	1	7
11. When I need to, I can say “no” to requests.	141	4.213	1.835	1	7
12. I can ask for help when I need it.	141	4.262	1.811	1	7
2. I find family can be supportive and understanding in preventing or recovering ...	135	4.237	1.893	1	7
6. I can access external resources (such as disability services, child-care respite) if I need them.	128	4.758	1.927	1	7
4. I find colleagues can be supportive and understanding in preventing or recovering ...	114	5.07	1.759	1	7
Consequences Items					
19. Doubting my abilities	141	1.801	1.305	1	7
16. Ongoing issues with fatigue	141	1.879	1.198	1	7
17. Ongoing issues with self-confidence	140	1.864	1.331	1	7
18. Ongoing issues with self-esteem	140	1.95	1.431	1	7
9. Worse financial situation	134	2.172	1.592	1	7
13. Worse physical health	139	2.194	1.488	1	7
10. Loss of valued activities that I enjoyed participating in	140	2.2	1.46	1	7
2. Loss of work opportunities	131	2.214	1.66	1	7
6. Loss of relationships with friends	138	2.304	1.55	1	7
15. Becoming traumatized by the events leading up to my burnout	139	2.424	1.757	1	7
12. Loss of skills and abilities	141	2.504	1.57	1	7
3. Loss of trust in health professionals	137	2.657	1.837	1	7
8. Loss of relationships with colleagues	126	2.659	1.621	1	7
5. Loss of trust in important people in my life	139	2.827	1.757	1	7
4. Loss of trust in the welfare system	113	2.991	1.81	1	7
1. Loss of my job	123	3.081	2.194	1	7
7. Loss of relationships with family	138	3.13	1.929	1	7
21. Frequently contemplating suicide	134	3.828	2.15	1	7
20. Self-harm	129	4.093	2.138	1	7
14. Becoming addicted to medications or drugs	120	4.8	2.032	1	7
22. Attempting suicide	117	5.402	1.983	1	7

We identified two themes relating to support and recovery. In (1) *seeking assistance*, (1a) *Useful therapies* included “talking to a therapist” and “Art Therapy - it regulates my

emotions AND tells me what they are”. Some wanted a “way of accessing respite” such as “autistic clinics... where we can retreat to get well, not with other mental health or disability”. What is perceived to be useful, however, may be specific to the circumstance and individual preferences: “I don’t like any type of talking therapy / counselling”. More commonly, professionals were perceived to be ill-equipped in the area of autism, and highlighted a *(1b) lack of understanding and support*: “As a medical practitioner... most of my colleagues have no idea about autism” and “I would like to see medical services understand autistic burnout and stop misdiagnosing as depression”. Many called for upskilling of health practitioners, with the difficulties described in health practitioner interactions often relatable to a *perspective disconnect*:

I spent two years talking to a psychologist who related to me as though I had significant psychosocial problems. It was pretty confusing and painful to me. I was offered antipsychotic medication... ultimately insulting and damaging ... talking to a person who I felt was actually not talking to or helping me, ME. I won't be doing that ever again.

This aspect of an *(1c) unaccommodating neurotypical world* was also often reported regarding the workplace: “the perception of Autism needs to change in the workplace. There needs to be some kind of way to encourage employers to see the benefits rather than the weaknesses of hiring people on the Autism Spectrum Disorder.”

There were a variety of additional strategies and environmental considerations outlined by participants describing *(2) What is needed for recovery*. Many strategies were both *(2a) protective*: “routine and familiarity, being alone, only engaging in activities that are familiar and feel safe” and / or *(2b) restorative*: “Sleep, quiet, physical exercise, walks in nature”. Frequent references were made to *(2c) animals, nature, water and low sensory*

environments: “pets, cats, garden, walk in the ocean, Aquarobics, water and music is very soothing”, “warmth, showers, fluffy textures, cats, scented candles”, “peace and quiet and being left alone in nature”. While for some “being around people I love (but not interacting)” was helpful, more often (2d) *space and time* was needed including: “An enormous time alone with as much sensory deprivation as possible” or “just complete withdrawal ... minimal socialising or contact with others, space to process everything and time”. For some recovery was (2e) *incomplete*: “I don’t ever feel truly recovered” leading to a need to “reassess my life”. Worryingly, reference was made to “each episode leads me closer to suicide”.

Misdiagnosis

When asked if autistic burnout is a better explanation for previous diagnoses, of 96 responses, 59 (61%) said yes, 21 (22%) said no, 2 (2%) were unsure, 23 (24%) additionally or separated reported on co-occurring conditions and 4 (4%) remained uncoded due to ambiguity. Many mentioned multiple perceived misdiagnoses, with depression ($n=38$; 40%) and anxiety ($n=19$; 20%) the most reported, followed by bipolar disorder ($n=8$; 8%), borderline personality disorder ($n=7$, 7%), chronic fatigue ($n=4$; 4%), OCD ($n=4$; 4%), panic disorder ($n=4$; 4%), social anxiety ($n=4$; 4%) and post-traumatic stress disorder ($n=3$; 3%), amongst the more frequently mentioned conditions. Qualitative responses highlighted the potential misdiagnoses that could be avoided by recognition of autistic burnout: “I was misdiagnosed with bipolar ... also burnout is still blamed on depression but I know the difference.”

Frequency and duration of autistic burnout

Forced-choice questions on frequency and duration of autistic burnout suggested varied experiences, with no strong pattern evident (see Tables 6 and 7).

Table 6

Frequency of a period of autistic burnout (n=136)

	n (%)
Daily	3 (2)
Few times per week	23 (17)
Weekly	7 (5)
Few times per month	11 (8)
Monthly	16 (12)
Few times per year	43 (32)
Less than once a year	25 (18)

Table 7

Typical, shortest and longest duration of an experience of autistic burnout (n=141)

	Typical n (%)	Shortest n (%)	Longest n (%)
Hours	7 (5)	31 (22)	2 (1)
1-2 Days	24 (17)	42 (30)	4 (3)
3+ Days	17 (12)	16 (11)	6 (4)
1-2 Weeks	20 (14)	10 (7)	12 (9)
3+ Weeks	8 (6)	6 (4)	9 (6)
1-2 Months	19 (14)	9 (6)	16 (11)
3+ Months	16 (12)	6 (4)	33 (24)
Year or longer	11 (8)	4 (3)	46 (33)
Don't know / other	17 (12)	14 (10)	11 (8)

In content and thematic analysis of duration and frequency open-ended item responses, a total of 26 (41%) participants who responded said duration had increased, 26 (41%) said it had decreased, and 11 (17%) said it stayed the same. Frequency increased for 24 (77%) participants who responded and decreased for 7 (23%). We identified five themes including (1) *getting older* (“The older I get the more severe the burnout”) and (2) *increased life demands* (“My ability to cope has decreased over time as life demands have increased”). Additional themes of (3) *autism diagnosis*, particularly recent diagnosis, brought (4) *awareness and understanding*: “Yes! They [autistic burnout experiences] have decreased ... since my autism diagnosis as I’m now in the position to identify them and make changes to reduce them”. Some described developing (5) *self-management* strategies that reduced

frequency or duration: “I experience it [autistic burnout] frequently, but have strategies for self-care that enable me to ‘reset’ whenever I need to.”

Discussion

This study attempted to deepen understanding and validate emerging definitions of autistic burnout, by surveying participants with lived experience of autistic burnout with a series of items aligned to the content of emerging definitions. The definition arising from Higgins et al. (2021) appears to more thoroughly describe the characteristics of autistic burnout endorsed by participants, though it is not incompatible with the definition from Raymaker et al. (2020). Specifically, many participants endorsed a mismatch between expectations and demands, a key element of the Raymaker et al. (2020) definition, associated with exhaustion, overload, and unaccommodating environments, but not necessarily a lack of personal abilities, as implied by the wording used in their definition. Withdrawal, masking and executive functioning problems described Higgins et al (2021) definition were strongly endorsed, though are absent from the Raymaker et al. (2020) definition. Duration and frequency of autistic burnout remain difficult to define with clear parameters, where Raymaker et al. (2020) specifies a 3+ months duration without clear justification. Both chronic and acute episodes are experienced by participants, which could confuse future research efforts to delineate duration parameters. Autistic burnout frequently emerges from problematic dynamics found in the interface between autistic and non-autistic individuals, and is often misdiagnosed.

In referring to autistic burnout, we acknowledge that terms such as ‘syndrome’ can be stigmatizing, and a medical model approach has been problematic in the history of our understanding of autism (Pellicano & den Houting, 2022). However, we aim for autistic

burnout to become recognised as a diagnosable syndrome, given high rates of misdiagnosis. Despite positioning autistic burnout within psychiatric nosology, it is important that a biopsychosocial perspective is maintained with a continued focus on the societal drivers of the syndrome.

Although there was strong endorsement across a range of suspected characteristics of autistic burnout based on emerging literature, quantitative data failed to define clear parameters on duration and frequency of autistic burnout. This was corroborated by the qualitative data, however, which highlighted a key difference between the Higgins et al. (2021) and Raymaker et al. (2020) definitions. Where Higgins et al. (2021) refers to “chronic episodes of autistic burnout may be preceded by brief or intermittent episodes” Raymaker et al. (2020) states “...long-term (typically 3+ months) exhaustion...” though it is unspecified how this duration was arrived at. Future work is needed on the specificity of the autistic burnout syndrome criteria, with the current results suggesting both extended and brief episodes are possible. Similarly, Phung et al. (2021) interviewed eight children and youth, finding no distinction between autistic burnout and shutdown, which might suggest an overarching autistic exhaustion syndrome.

Other differences between the Higgins et al. (2021) and Raymaker et al. (2020) definitions were emphasised by highly-endorsed items. First, social withdrawal was the third most highly-endorsed item relating to the autistic burnout experience, second only to items regarding exhaustion, with no participant being neutral or in disagreement to this item. As noted in Higgins et al. (2021), we suggest that social withdrawal is a key characteristic of this syndrome that is missing from the Raymaker et al. (2020) definition. Second, with regard to the potential mismatch between expectation and abilities, no participants commented on a personal lack of ability; instead, exhaustion and a lack of respite led to the difficulty meeting neurotypical expectations. We suggest the wording used by Raymaker et al. (2020) is

potentially problematic in positing a deficit in autistic people, rather than a lack of accommodation and understanding by non-autistic people. Third, executive function difficulties, and reduced abilities to mask, were both strongly endorsed characteristics that are less apparent in the Raymaker et al (2020) definition. Fourth, the majority of participants endorsed experiencing an increase in stimming behaviours, in addition to heightened sensory sensitivities, aligning to the concept in Higgins et al. (2021) of “increased intensity of autistic traits”. Finally, the recurring theme of *perspective disconnect* highlights the need for appropriate, not just “adequate” supports as described in Raymaker et al. (2020).

Qualitative data highlighted the difficulties that occur in interactions between autistic and non-autistic people, leading to the theme of *ableism*, and the recurring theme of *perspective disconnect*. *Perspective disconnect* refers to the fundamental difference and disconnect in perspective taking in people with a different existential experience of life, leading to a lack of flexibility in providing accommodation or demonstrating compassion. Similar to the postulated autistic mind-blindness (Baron-Cohen, 1995), a term that we do not endorse, where we could have referred to a neurotypical mind-blindness, the theme was named *perspective disconnect* to demonstrate commonality in difficulties encountered by both autistic and non-autistic persons in understanding each other, even though in our study with autistic participants we only had data describing one side of this dynamic. This disconnect has been proposed within Milton’s (2012) double empathy problem and by the two-sided perspective-taking discussed by Heasman and Gillespie (2018), with a potential means to understanding this *perspective disconnect* using relevance theory described by Williams et al. (2021). Participants reported having their concerns ignored, feeling not being believed or understood. The indirect manner of non-autistic expression with both implied and explicit meanings can confuse the autistic, conversely the direct manner of autistic expression may interfere with receptivity of the non-autistic communication partner or be misinterpreted as

exaggeration. The seriousness and urgency of having unmet needs addressed remains unrecognised by the non-autistic, leaving the autistic feeling that their concerns have been misunderstood, dismissed or trivialised. This disconnect was experienced across onset and recovery, and could be an area to address in the upskilling of non-autistic health practitioners (Mitchell et al., 2021). Further, increased awareness within health practitioners may reduce the rate of 61% of participants perceiving they had been previously misdiagnosed.

Participants also highlighted nature, water and animals in their recovery pathway, which has been promoted as therapeutic for autistic children (e.g. O’Haire, 2013; Pan, 2010), yet with apparently underexplored benefits for autistic adults, in addition to the need for space, time and lower arousal. Advocacy from clinicians and autistic people is needed to further recognition, research on autistic burnout and appropriate accommodations. Autistic adults should pursue what works best for them in recovering energy whilst research is forthcoming, however, suggestions from our participants may be of assistance.

Limitations

One primary limitation of the study is the inability to screen participants for a confirmed diagnosis of autistic burnout, given as yet no validated definition or screening tools for the syndrome exist. However, the strong endorsement of core characteristics by all participants suggested good content validity of emerging definitions and an underlying core phenomenon being reported on. We were also unable to clinically confirm autism diagnosis, though all participants were above cut-off on the AQ-28 except two participants only one or two points below cut-off. The preponderance of female participants and participants not identifying as male or female is of interest, and although a potential limitation, larger studies not recruiting specifically for autistic burnout are needed to determine if there are relationships between gender and prevalence of autistic burnout, or if the gender bias in our sample is more related to the higher female participation in online autism research (Arnold et

al., 2019). Being an online survey that was promoted including via social media, gender ratios, mean age and recency of diagnosis in this sample could also be a result of the sampling strategy. The study was promoted via the ALSAA newsletter, with the ALSAA study having an inclusion criteria of age 25+ years. The study was also promoted through social media, with those more recently diagnosed being possibly more likely to be engaged with online autism discourse. Future research is needed to disambiguate the chronic and acute experiences reported by participants.

Conclusion

Autistic burnout is a debilitating syndrome preceded by an overload of life stressors and the daily challenge of existing in a neurotypical world, frequently misdiagnosed as depression, anxiety, bipolar disorder, borderline personality disorder or other conditions. This work further investigates autistic burnout, which, in our study, was more closely aligned with the description by Higgins et al. (2021). This work adds further evidence to aid future assessment tool development. More work is needed to increase clinician awareness (Lipinski et al., 2021), particularly on issues of the double-empathy problem (Milton, 2012; Mitchell et al., 2021) and differentiation of autistic burnout from other conditions including autistic shutdown (cf. Phung et al., 2021). Change is needed to promote inclusion (Weaver et al., 2021) and address the unaccommodating neurotypical environments that appear to be driving autistic burnout. Co-production and longitudinal research with autistic adults are needed to determine supports and strategies that are beneficial to recover from autistic burnout.

References

Arnold, S. R. C., Foley, K.-R., Hwang, Y. I., Richdale, A. L., Uljarević, M., Lawson, L., Cai, R. Y., Falkmer, T., Falkmer, M., Lennox, N. G., Urbanowicz, A., & Trollor, J. N.

- (2019). Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA). *BMJ Open*, 9(12), e030798. <https://doi.org/10.1136/bmjopen-2019-030798>
- Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of mind* (pp. xxii, 171). The MIT Press.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5–17. <https://doi.org/10.1023/A:1005653411471>
- Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8–14. <https://doi.org/10.1016/j.npls.2016.01.001>
- Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0071>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity*, 56(3), 1391–1412. <https://doi.org/10.1007/s11135-021-01182-y>
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9(1), 42. <https://doi.org/10.1186/s13229-018-0226-4>
- Endow, J. (2017, March 9). Autistic burnout and aging. *Aspects of Autism Translated*. <http://www.judyendow.com/autism-and-aging/autistic-burnout-and-aging/>

- Heasman, B., & Gillespie, A. (2018). Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*, 22(6), 740–750. <https://doi.org/10.1177/1362361317708287>
- Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism*, 13623613211019858. <https://doi.org/10.1177/13623613211019858>
- Hoekstra, R. A., Vinkhuyzen, A. A. E., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., Posthuma, D., & van der Sluis, S. (2011). The construction and validation of an abridged version of the Autism-Spectrum Quotient (AQ-Short). *Journal of Autism and Developmental Disorders*, 41(5), 589–596. <https://doi.org/10.1007/s10803-010-1073-0>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, 49(4), 559–572. <https://doi.org/10.1017/S0033291718002283>
- Howard, K. J. (2018). Emergence of a new method: The Grounded Delphi method. *Library and Information Research*, 42(126), 5–31. <https://doi.org/10.29173/lirg746>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). “Putting on My Best Normal”: Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519–2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Lawson, W. B. (2020). Adaptive Morphing and Coping with Social Threat in Autism: An Autistic Perspective. *Journal of Intellectual Disability - Diagnosis and Treatment*, 8(3), 519–526. <https://doi.org/10.6000/2292-2598.2020.08.03.29>

- Lipinski, S., Boegl, K., Blanke, E. S., Suenkel, U., & Dziobek, I. (2021). A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum. *Autism*, 13623613211057972. <https://doi.org/10.1177/13623613211057973>
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91(1), 1–20. <https://doi.org/10.1348/000712600161646>
- Milton, D. (2012). On the ontological status of autism: The ‘double empathy problem.’ *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*, 39(1), 1–18. <https://doi.org/10.1111/bjdp.12350>
- Nicolaidis, C., Raymaker, D. M., McDonald, K. E., Lund, E. M., Leotti, S., Kapp, S. K., Katz, M., Beers, L. M., Kripke, C., Maslak, J., Hunter, M., & Zhen, K. Y. (2020). Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations. *Autism in Adulthood*, 2(1), 61–76. <https://doi.org/10.1089/aut.2019.0074>
- O’Haire, M. E. (2013). Animal-Assisted Intervention for Autism Spectrum Disorder: A Systematic Literature Review. *Journal of Autism and Developmental Disorders*, 43(7), 1606–1622. <https://doi.org/10.1007/s10803-012-1707-5>
- Pan, C.-Y. (2010). Effects of water exercise swimming program on aquatic skills and social behaviors in children with autism spectrum disorders. *Autism*, 14(1), 9–28. <https://doi.org/10.1177/1362361309339496>

- Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. <https://doi.org/10.1111/jcpp.13534>
- Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What I wish you knew: Insights on burnout, inertia, meltdown, and shutdown from autistic youth. *Frontiers in Psychology*, 12, 4981. <https://doi.org/10.3389/fpsyg.2021.741421>
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). “Having all of your internal resources exhausted beyond measure and being left with no clean-up crew”: Defining autistic burnout. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2019.0079>
- Rose, K. (2018, May 21). *An autistic burnout—The autistic advocate*. <http://www.theautisticadvocate.com/2018/05/an-autistic-burnout.html>
- Weaver, L. A., Bingham, E., Luo, K., Juárez, A. P., & Taylor, J. L. (2021). What do we really mean by “inclusion?”: The importance of terminology when discussing approaches to community engagement. *Autism*, 25(8), 2149–2151. <https://doi.org/10.1177/13623613211046688>
- Williams, G. L., Wharton, T., & Jagoe, C. (2021). Mutual (mis)understanding: Reframing autistic pragmatic “impairments” using relevance theory. *Frontiers in Psychology*, 12. <https://www.frontiersin.org/articles/10.3389/fpsyg.2021.616664>

Supplementary Table 1: Additional Quotes Supporting Thematic Analysis

Section / Theme	Quote(s)
Exploring a mismatch between expectations and ability	
(1) Ableism	<p>“Too many social plans e.g. when covid restrictions lifted and I felt the pressure to attend multiple social gatherings and avoid lying to get out of invitations.”</p> <p>“Mismatch between family and peers expectations of me due to previous accomplishments, and the ability to repeat them or match them in the future. Therefore, the peers/employers/family are disappointed in your effort.”</p>
(2) Perspective disconnect	<p>“Difficulties communicating my experience and overload leading to more expectations being placed upon me.”</p> <p>“Being unable to communicate well in my relationship and feeling misunderstood and not listened to.”</p>
(3) Lack of consideration and lack of support	<p>“Having no family who know or understand anything about ASD or mental illness and being excluded because of their ignorance and lack of support.”</p> <p>“Unable to access appropriate supports for myself and my son, can’t get a break from my carer role to my son.”</p>
Characteristics of onset	
(1) Physical signs of onset	<p>“When my eating gets worse”</p> <p>“I notice I have difficulty saying words. I don’t forget them... they are in my brain but I can’t get them to my mouth”</p>
(2) Difficulties in recognition	<p>“Don’t know it’s happening until you say out loud that I need a break and a weekend doesn’t count.”</p> <p>“I don’t usually realise I am burnt out until it is ‘too late’. When I can’t get out of bed, my head is heavy, things feel low, I have a smaller tolerance for things, I become socially withdrawn, I can’t do much in my day.”</p>
(3) Chronic and acute episodes	<p>“There are major and minor burnouts of differing severity. I am unsure how to linguistically distinguish them apart from major and minor burnout but they are quite different while still being considered burnouts.”</p>
(4) Attempts to avoid full burnout	<p>“It can be sudden, but is usually not a surprise, that is, so long as I have a certain degree of control over myself and my environment I can manage my way around onset signs and avoid the full burnout.”</p> <p>“Social demands in direct contradiction to my instructions will catalyse burnout and extend its duration.”</p>

(5) Intense engagement	<p>“Different things to juggle and not enough time to hyperfocus on my interests.”</p> <p>“Overwhelming need to micromanage all aspects of my day.”</p>
(6) Unaccommodating environments	
(6a) Community / interpersonal	<p>“Being misgendered suffering gender identity body dysphoria 24/7 daily.”</p> <p>“Difficulty socialising with neurotypicals (who don’t understand me) for too long.”</p>
(6b) Socio-political structures and systems	<p>“Stress related to NDIS and the mental health system.”</p> <p>“Centrelink. Their robot voice auto-telephones”</p>
(6c) Workplace	<p>“It is overwhelming and until COVID I had NO (sic) idea how much my work environment impacted.”</p> <p>“burnouts triggered by... full time work in an office job where I needed to talk to people all the time, plus constant sensory overload ... and being sexually harassed by three different managers ...”</p>

Characteristics of recovery, support and consequences

(1) Seeking assistance	<p>“I ask for help, but people don’t take it seriously. Then when I completely hit burn-out they say I should have been more open about how I was feeling.”</p> <p>“I don’t think you should avoid tolerable discomfort but asking for assistance from NTs to avoid INTOLERABLE discomfort is very hard. Autistics don’t lie about how we feel we don’t see the point if I’m telling you I need you to cut me some slack it breaks me that my character/capacity would be questioned.”</p>
(1a) Useful therapies	<p>“The only ones who could help are professionals who are Autistic themselves. There are no openly Autistic professionals in Sydney.”</p> <p>“... talking to a therapist/mentor, exercise /yoga.”</p>
(1b) Lack of understanding and support	<p>“ I can access counselling, however, finding ASD specialists locally is impossible! Counsellors and psychologists that don’t know autism are useless to me!... .. I would only see a counsellor who specialises, legitimately in Autism.”</p> <p>“I would like to see medical services understand autistic burnout and stop misdiagnosing as depression. Then it would be easier to get the help needed.”</p>
(1c) Unaccommodating neurotypical world	<p>“It is very hard to get accommodations at work. ASD and mental health conditions are not well understood.”</p>

	<p>“There needs to be Autistic Clinics that can help us. Places we can go retreat to to get well, not with other mental health or disabilities.”</p>
(2) What is needed for recovery	
(2a) Protective	<p>“I am going to get an assistance dog which I believe will help me have more capacity, feel safer more often and remind me to self-regulate.”</p> <p>“Free time to actually do things and challenge myself.”</p>
(2b) Restorative	<p>“Being able to withdraw from the world without and then come back at my own pace without being pressured or feeling guilty is probably one of the biggest things for me.”</p> <p>“anything that doesn’t involve expectations from others.”</p>
(2c) Animals, nature, water and low sensory environments	<p>“Stay in sensory protective environment. Help to reduce my internal demands, e.g. achieving routines, keeping cleanliness standards etc. I must have to feel calm.”</p> <p>“Nature, pets, cats, garden, walk in the ocean, Aquarobics, water and music is very soothing.”</p>
(2d) Space and time	<p>“Space and time. Respite away from anyone else would speed it up.”</p> <p>“Assured time spent alone is the most powerful and beneficial thing for me. It’s difficult for me to get.”</p>
(2e) Incomplete	<p>“It’s completely overwhelming and I don’t know if I will survive it.”</p> <p>“I think perhaps my current state is not expecting recovery”</p>
Frequency and duration of autistic burnout	
(1) getting older	<p>“The older I get the more severe the burnout. It is like ... I haven’t had a chance to refill my fuel tank before I again run out of petrol.”</p> <p>“they have gotten far worse and more frequent as I’ve aged.”</p>
(2) increased life demands	<p>“Yep. They have increased since becoming a parent.”</p> <p>“Yes! Dependent on stressors eg. Last year I was studying full time and burnout was frequent and severe this year, I haven’t worked and burnout is less frequent and a little less severe.”</p>
(3) autism diagnosis	<p>“Being diagnosed has helped me to understand what has been happening to me however unless I’m completely alone I’m vulnerable and there is no professional help available.”</p> <p>“Increase over time pre-diagnosis then slowly decreasing with lifestyle changes to prevent burnout.”</p>

(4) awareness and understanding	<p>“Changed. Because I have knowledge of them (autistic burnouts) now and don’t misrepresent them as depression episodes or other burnout.”</p> <p>“Duration shorter since understanding triggers and identifying more possible solutions for increased coping. More severe during Covid lockdown.”</p>
(5) self-management	<p>“Changed overtime with better management of Autism - related issues.”</p> <p>“I’m more aware of the signs to look for and can cut things off at the pass if I’m careful.”</p> <p>“Severity has decreased as I have become more aware and take steps to avert it (autistic burnout).”</p>
