

Defining Autistic Burnout Through Experts by Lived Experience: Grounded Delphi Method Investigating #AutBurnout

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Abstract

Although commonly described on social media by autistic people, there is little recognition of autistic burnout in the academic literature. Anecdotally, autistic burnout is described as a debilitating condition that severely impacts functioning, is linked to suicidal ideation, and driven by the stress of masking and living in an unaccommodating neurotypical world. We sought to define autistic burnout using Grounded Delphi Method. Autistic adults, experts by lived experience of autistic burnout ($n=23$), co-produced and agreed to a definition intended for clinicians and the autistic and autism communities. A thick description (Geertz, 2017) and conceptual framework was developed from the open-ended round 1 survey, with a high majority of agreement reached in the round 3 survey. 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. Further work is needed to differentiate autistic burnout from other conditions and to build clinician understanding of the accompanying complexity to be considered in treatment planning.

Introduction

Autistic burnout is an experience commonly described by autistic people (e.g., #AutBurnout, #AutisticBurnout on social media) and reported to have substantial, deleterious effects on people's lives. Autistic people link autistic burnout to 'camouflaging' or 'masking', and the exhaustion of "putting on my best normal" (Hull et al., 2017, p. 2519) in an unaccommodating world. Anecdotal accounts describe aggravation of co-occurring health conditions, suicide ideation and attempts. Yet, until very recently, this phenomenon has not garnered any interest in the academic literature (Raymaker et al., 2020). In the words of one autistic self-advocate, "Burnout is an integral part of the life of an Autistic person... Yet nobody, apart from Autistic people, seems to know about it" (Rose, 2018).

First described by Freudenberger as "becoming exhausted by making excessive demands on energy, strength, or resources in the workplace" (1974, p. 159), non-autistic burnout has since resulted in a wealth of research (Heinemann & Heinemann, 2017; Korczak et al., 2010; Kristensen et al., 2005; Maslach & Leiter, 2016). It is not classified in the DSM-5 and appears in the ICD-10 and ICD-11 as an occupational phenomenon and is not classified as a specific medical condition (World Health Organization, 2019), and is instead included in the chapter listing reasons for which people contact health services that are not health conditions. Critically, drawing on the seminal work of Maslach (Maslach & Leiter, 2016), the ICD-11 characterises burnout specifically within the context of unmanaged work-related stress, which results in three components of perceived exhaustion, mental distance or cynicism from one's employment, and perceived reduced professional efficacy. Complicating this area further, the Swedish version of the ICD-10 incorporates "exhaustion disorder", attempting to facilitate

diagnosis of more significant burnout, attributed to work or personal life (Adamsson & Bernhardsson, 2018), with criteria covering exhaustion, reduced mental energy, concentration problems, reduced functional capacity, emotional instability, sleep problems and physical symptoms including increased sensitivity to sound. Others have also argued for burnout not limited to occupational stress (Grossi et al., 2015). There are significant overlaps with conditions such as “chronic fatigue syndrome” which appears in both the international versions of ICD-10 and 11, with elements of exhaustion and concentration problems common across these diagnoses, though no firmly established biomarkers, and diagnosis by exclusion.

In contrast to the description in the ICD-11, the academic definition of burnout remains “vague and blurry” (p. 10, Heinemann & Heinemann, 2017; Korczak et al., 2010). The construct has largely come to be defined by the most influential and popular measurement tool, the Maslach Burnout Inventory (MBI; Maslach et al., 1986) and its variants. However, a plethora of measurement tools have been developed each having unique conceptualisation and areas of emphases (e.g. Copenhagen Burnout Inventory; Kristensen et al., 2005; School Burnout Inventory; Salmela-Aro et al., 2009; Athlete Burnout Questionnaire; Sharp et al., 2010). There is ongoing debate about whether burnout constitutes a distinct clinical diagnosis, specific to occupational stress and separate from depression (Bianchi et al., 2015; Heinemann & Heinemann, 2017). On the one hand, it is argued that burnout is a distinct (Maslach & Leiter, 2016) and useful target for further research and intervention given the high prevalence rates and social familiarity with which burnout is discussed in many industrialised countries. On the other hand, and contrary to earlier research (Schaufeli et al., 2001), a recent large study ($n=3,113$) concluded that the purported burnout-depression distinction is artificial (Bianchi et

al., 2020). This study used three burnout measures including two versions of the MBI, as well as the Patient Health Questionnaire – 9 (PHQ-9; Kroenke et al., 2001), finding a single overarching depression factor. Another large study (n=1,258; Verkuilen et al., 2020) using structural equation modelling on the PHQ-9, MBI and other tools also concluded burnout lacked discriminant validity and recommended clinicians assess for depression when individuals present with a complaint of burnout.

Whilst existing research on burnout is isolated to the workplace, autistic burnout is described anecdotally as pervasive and appears to be a response to coping with the basic demands of everyday life. Considering the symptoms reported, autistic burnout may not be simply a variation of mainstream (non-autistic) burnout phenomena or depression. In contrast to work-related non-autistic burnout, it is suggested the fatigue of ‘masking’ and / or ‘camouflaging’ autistic behaviours, and stress of living in an unaccommodating neurotypical world (Frost et al., 2019; Hull et al., 2017; Livingston et al., 2019; Mandy, 2019) are the key drivers of autistic burnout. According to autistic advocates, burnout can involve the progressive loss of speech, social skills, memory capacity, executive function, self-care capabilities and a reduced ability to cope with sensory overload (Boren, 2017; Rose, 2018). Autistic advocates have unsurprisingly called for more research on this phenomenon (Rose, 2018).

The only study conducted thus far reviewed (n=19) social media accounts, and conducted (n=9) interviews focused on autistic burnout, in addition to secondary analysis of (n=10) interviews from a previous employment study (Raymaker et al., 2020). Using thematic analysis and a community-based participatory research approach, they defined autistic burnout as:

... a syndrome conceptualized as resulting from chronic life 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.

Anecdotally, autistic burnout has also been misdiagnosed as depression and, whilst symptoms can mirror those of depression, Raymaker et al. (2020) suggest that it is a distinct condition.

The definition published by Raymaker et al. (2020) was not available at the time of our study and has yet to be validated. Using a Grounded Delphi Methodology (GDM; Howard, 2018), our study, co-produced by autistic and non-autistic researchers, aimed to develop a consensus definition of autistic burnout for clinical and research purposes, differentiated from non-autistic burnout and depression. A definition of autistic burnout by consensus of ‘experts by lived experience’ would (i) provide acknowledgement and formal recognition, (ii) enable research towards further understanding its causes, correlates, and consequences, and (iii) identification of appropriate support strategies and environmental accommodations. In recognition of their expertise, we refer to ‘experts’ rather than ‘participants’ throughout this article.

Methods

Recruitment

Experts were recruited through social media advertisement and the Australian Longitudinal Study of Autism in Adulthood (ALSAA; Arnold et al., 2019) quarterly newsletter. To be included, adults had to: 1) have an independent clinical diagnosis of autism; 2) be living in Australia; 3) have had a personal experience of autistic burnout; 4) have the ability to give independent,

informed consent; and 5) be able to complete surveys with minimal assistance. Experts gave consent via an online registration form, and then were given an expert identifier code and link to the round 1 survey. We provided experts with the option to complete the surveys online or via hardcopy or email. The study was approved by the [blinded for review]. Experts were given a gift card (AUD \$50) for each round of survey participation.

Experts

Twenty-seven people registered, all of whom met the above inclusion criteria. One person without a formal diagnosis of autism expressed interest but was excluded. Four experts withdrew with most citing fatigue from burnout, which prevented participation, leaving 23 experts (85%) who responded across three rounds of survey (round 1: $n=21$, round 2: $n=22$, round 3: $n=21$). The majority of participating experts reported Caucasian ethnicity, with others reporting Asian ($n=1$), Hispanic ($n=1$) and Germanic ($n=1$) ethnicity. To ensure accessibility, we invited experts who did not complete round 1 or only gave partial responses to participate in later rounds. Experts ranged in age from 27 – 64 years (M age = 42.8 years, $SD = 9.9$). Age at time of diagnosis ranged between 4 – 61 years (M age = 36.8 years, $SD = 12.8$). The majority of experts reported female gender ($n=16$; 69.6%) with a smaller proportion of males ($n=6$; 26.1%) and one person reporting non-binary gender (4.3%). At the time of the round 1 survey, 87% of the experts had attained a tertiary education and 13% had attained a secondary education. Most of the sample was employed (full-time employment: 43%, part-time employment: 30%), while the rest were unemployed (17%), volunteers (4%) or retired (4%).

Re-verification of autism diagnosis was not undertaken due to the geographic spread of participants across Australia and resource availability. All experts, however, scored above cut-off on the Autism Quotient-28 (AQ-28; Hoekstra et al., 2011) (cut-off >65; $M = 92.3$, $SD = 10.2$, range 71 – 108).

Procedures

The current study adopted the Grounded Delphi Method (GDM; Howard, 2018), which is a relatively new methodology incorporating aspects of grounded theory into Delphi study processes (Päivärinta et al., 2011). The combination of Delphi method, useful in areas with little established literature (Howard, 2018), and grounded theory, useful for theory building (Päivärinta et al., 2011), was well-suited to address the aims of the current study.

Experts completed three separate rounds of survey, over a six-month period. Grounded theory approaches to analysis were applied to the open-ended responses arising from the round 1 survey to develop an initial draft definition of autistic burnout. In round 2, experts were asked to endorse and comment on the elements of the draft definition created by the researchers based on the round 1 responses. In round 3, experts were asked to endorse changes identified from the round 2 survey. See Figure 1 for a study flow outline.

INSERT FIGURE 1 ABOUT HERE

To aid anonymity, experts were not linked across rounds. In rounds 2 and 3, consensus required at least 50% quantitative data agreement, with no major qualitative data disagreement. In comparison to the majority of Delphi studies, which often use a consensus rate of 80%, we reduced the criterion to be more inclusive in recognition of the heterogeneity of autistic adults.

In each round, a summary of findings from the previous was shared with experts, prior to surveying their responses to the developing definition.

Instruments

The round 1 survey gathered demographic and diagnostic information. It then asked a series of open-ended questions, covering what autistic burnout means to the person, their experience(s) of autistic burnout, recovery, impact on autistic traits and changes in self-image (see Supplementary Materials). To compare with concepts of mainstream burnout, additional open-ended questions asked about confidence in abilities, cynicism and depersonalisation. A specific open-ended question probed for differences between autistic burnout, depression and being sick. A final question asked if any support was received to complete the survey. The survey began and ended with instructions including contacts for queries or if the expert experienced distress.

The round 2 survey asked a series of Visual Analogue Scale (VAS) questions on agreement for each element, or sub-element, of the draft definition arising from round 1. The VAS items were adaptations of a 7-point Likert scale typically used in Delphi studies, though presented on a sliding scale from 0 (strongly disagree) – 100 (strongly agree) in an attempt to be more autism friendly, with the word 'Agree' appearing at the 80% mark. VAS question blocks linked directly to sections of the draft definition. Question blocks covered onset, characteristics, additional elements, recovery and differential diagnosis, with each question block ending with an open-ended question asking for comments or suggestions (see Table 3 and Supplementary materials).

There were also multiple-choice questions relating to duration, and a final open-ended overall comments question.

To gain endorsement to changes made to the definition by the research team arising from round 2, the round 3 survey asked similar VAS question blocks followed by an open-ended comments question (see Table 4). There was also a final VAS question and open-ended question asking how much the draft definition describes your experience(s) of autistic burnout.

Co-production

Autistic burnout was identified as the topic of interest by the autistic (JH) and non-autistic (SA) co-authors, with GDM identified conducive to theory development and the exploratory nature of this autistic burnout study. This particular study positions autistic adults as experts by experience. JH and SA jointly worked through all stages of the research to accommodate “different dispositional outlooks and personal conceptual understandings” (Milton et al., 2018, p. 1) likely to occur between neurotypical and neurodivergent researchers. JH and SA collaborated in all stages of the research from grant and ethics applications, development of surveys, definitions and analyses, and included frequent video conferencing throughout the project. At times where resolution was difficult to achieve, the input of JW was sought. Critical reviews, input and support was provided by all co-authors.

Data Analysis

Qualitative data were processed using NVivo 12 and quantitative data using SPSS 26, STATA 15 and Excel.

From the open-ended items in the round 1 survey, JH and SA jointly analysed responses. Peer researcher JH approached the data analysis from a background of being a late-diagnosed autistic. JH has been involved in research co-production for several years, including consulting to the Autism CRC and the Australian Longitudinal Study of Autism in Adulthood (ALSAA; Arnold et al., 2019) and has personally experienced autistic burnout. SA approached data analysis from the background of being a psychologist and disability researcher and clinician. Following grounded theory concepts, an inductive approach to coding was used based on semantic and latent meanings, seeking to identify an overall conceptual framework and basis for a definition of autistic burnout. To ensure no dominance of neurotypical or neurodivergent interpretations, open coding was first completed independently by JH and SA for all responses, then, across multiple video conferencing sessions, a consensus on the coding framework was reached and axial coding completed. There were also multiple sessions jointly coding the data. A high-level of consensus in coding between SA and JH was evident from recoding of a third of the responses using the finalised coding framework. JH went on to complete the coding of remaining responses. A brief journal log was kept for audit trail purposes.

JH and SA drafted an initial definition of autistic burnout which was then shared with all authors for review and input, prior to being shared with experts and used as the basis for the round 2 survey. In the round 2 analyses, qualitative responses were subjected to a basic template analysis (Brooks et al., 2015), focused on identifying whether changes to the definition were required. We calculated the percentage of experts who agreed or strongly agreed with each item. Based on qualitative responses and items that did not reach the agreed quantitative consensus criteria, a refined definition was developed. This definition was shared again with the

experts and formed the basis of the round 3 survey. To determine if consensus levels were reached, round 3 analysis followed the same template analysis of qualitative data and descriptive analysis of quantitative data.

Results

Round 1

Analysis of qualitative data generated a theory of autistic burnout composed of interlinked core, major and ancillary categories, an integrative diagram is presented in Figure 2. Each category had several subcategories (see Table 1), a brief narrative synthesis of these categories and subcategories is presented below (see Supplementary Materials – Table A for a glossary of words used in naming subcategories and example quotes). Notably, no experts mentioned occupational stress in their direct response to what autistic burnout means to them. Instead, they commonly referred to the stress of “being in a world that is not your world”.

INSERT FIGURE 2 ABOUT HERE

Table 1: Categories and subcategories from round 1 survey

Category	Subcategory
Energy	(E1) Autism pre-diagnosis
	(E2) Supportive environments
	(E3) Disempowered
	(E4) Lack of control
	(E5) Camouflaging - masking
Onset	(O1) Social interaction
	(O2) Misunderstanding by and of others
	(O3) Unexpected change
	(O4) Cognitive overwhelm & overload – demands exceeding capacity

	(O5) Sensory overwhelm & overload
	(O6) Work demands
Impact	(I1) Increased manifestation of autistic traits
	(I2) Difficulty with emotion processing
	(I3) Decreased functional capacity
	(I4) Cognitive disruption
	(I5) Confusion, dissociation
	(I6) Exhaustion
	(I7) Negative descriptions
	(I8) Self-image
	(I9) Trusting others (cynicism)
	(I10) Withdrawal – self isolation
	(I11) Suicide and Suicidal Ideation
Recovery (Strategies)	(R1) Tenacity – persevering
	(R2) Space needed
	(R3) Self-knowledge
	(R4) Time needed
	(R5) Planning pacing
	(R6) Lack of appropriate support
	(R7) Incomplete recovery
	(R8) Unique recovery strategy
Temporal qualities	(F1) One-off
	(F2) Intermittent
	(F3) Regular – ongoing
	(F4) Days - hours
	(F5) Weeks – months
Differentiating from depression	(C1) Similarities
	(C2) Differences

Core Category: Energy

Energy was the core overarching category; autistic burnout is directly related to the energy reserves of the autistic person at any point in time. *Energy* grouped together many concepts that contributed to or detracted from the expert’s “video game energy bar”. It was central to their autistic existential experience of burnout: “Autistic burnout is when I no longer have the

energy reserves necessary to act Neurotypical". This category was evident across *onset, impact and recovery from autistic burnout*.

For several experts, autistic burnout experience was *pre-autism diagnosis* (E1): "Afterwards, I saw a psychologist who referred me... I was diagnosed with [High Functioning Autism] HFA", whilst others reconceptualised their experience after diagnosis: "Before knowing I was autistic, I believed I was depressed but now as I'm understanding more about autism, I think I was actually in autistic burnout". Having a *supportive environment* (E2) impacted positively on energy levels, for example, "I have a good support from my family who have carried me along /forward over the 5 years", in contrast, "I reached out for help from others but everyone is too busy with their own issues, including medical professionals". *Disempowerment* (E3) was evident and energy draining for several experts: "I was given responsibility as safety officer at my workplace... gained the enmity of my co-workers has made me think I'd done the wrong thing after it had felt I'd done the right thing". Similarly, experts reported an exhausting and frustrating *lack of control* (E4): "I realised I was fighting battles... it did not seem to matter what I did I could not get people to listen or support us in the manner we wished. It was always under someone else's ridiculous terms or not at all".

In everyday life, the energy-draining nature of *camouflaging – masking* (E5) may not be visible to non-autistics: "People praise us for what we are capable of and what we have achieved thanks to our performance... but no one stops to consider the toll it takes on us". However, in *onset and impact* the amount of work put in to hide being autistic becomes apparent: "being in a world that is not your world and you have to change how you exist to make it all work".

Ultimately, experts reported not having the energy reserves to act and a state of stasis was

reached. Withdrawal from all interpersonal interactions occurred allowing the recovery process to commence restoring energy reserves: “I needed that time to recover and be myself unfiltered.”

Major Category: Onset

Onset incorporated subcategories of *social interaction* (O1): “social situations... you need to be kind of small-talky, and have to think of the right things to say and not saying anything too weird or make any silly jokes and look people in their eyes are exhausting”. Experts felt that it is within *social interaction* and communication that *misunderstanding by and of others* (O2) can occur. Misunderstandings for autistics cause stress, use *energy* and lead to onset of burnout: “strong increase in ability to translate between native ‘autistic’ and ‘neuronormal’ communication and mannerisms. Strong decrease in the tolerance for need to translate”. For some, *unexpected change* (O3) was the trigger for onset of autistic burnout: “Alternatively a large life event tips you way over because you can’t process this information as easy as others”. Experts referred to stressful life events including moving to a new country or accommodation, caring for others and co-occurring health problems, though “everyday stressors” were more commonly referenced. Being overloaded by cognitive inputs, or overcome by the intensity of life, was described in *cognitive overload & overwhelm – demands exceeding capacity* (O4): “Not being able to function due to being overwhelmed by life (particularly being autistic but having to live as a neurotypical)”. Overloading was also related to *sensory overload & overwhelm* (O5) and *social interaction* (O1), succinctly grouped together by some experts; “Autistic burnout means overload from sensory or social interactions” and “I think it may be a longer/more severe form of ‘overwhelm’. Unable to function, too many inputs that can’t be processed, both

sensory and social”. Finally, many commented on *work demands* (O6) as a contributing factor: “I was working long hours on a major project, also managing other IT tasks, with continual frustration with my CEO and third-party companies undermining my authority”.

Major Category: Impact

Impact ranged in severity, with an overall *increased manifestation of autistic traits* (I1): “I would just sit and cut pieces of leather into strips for hours on end, alone and in silence”. Experts also reported increased sensory sensitivity and aggravation of coexisting conditions, such as insomnia, anxiety, gastrointestinal problems: “I had always experienced depression and anxiety... But they built to self-injurious levels”. Importantly, reduced *energy* included a reduced ability to mask: “I couldn't keep acting the way people expected” with communication difficulties: “I experience selective mutism”. Burnout also impacted *difficulty with emotion processing* (I2), with some experts highlighting increased sensitivity, where others noted a perceived emotional numbness as opposed to heightened emotions: “Fight or flight reflex triggered by small things”, “I felt entirely numb”, “completely emotionally numb”, “not wanting to feel emotions”. Many commented on overall *decreased functional capacity* (I3), to the point of complete incapacitation: “I didn't really want to get out of bed each day. I wasn't able to do normal everyday things such as showering, cooking, cleaning”. The impact on functioning extended to *cognitive disruption* (I4) of some form: “Mental exhaustion”, “I forget everything I'm good at and see no hope for the future”. The *cognitive disruption* could be extreme, experienced as *confusion, dissociation* (I5), with some disconnecting from consciousness altogether: “I became unable to think, I'd cry all the time and go into a kind of fugue state. I thought I was going insane” and “I walked away from work and was found many hours later by

a security guard... I spent the next 3 weeks in the psychiatric ward... I felt numb ... I have barely any memory of the walk I took”.

Key to understanding the *impact* of autistic burnout is the *exhaustion* (I6) and loss of *energy* experienced, with one expert reporting that they felt “drained, depleted, fatigued”. There were many *negative descriptions* (I7) of events: “it was horrible” and pervasive: “everything I have to do feels like a weight pressing on my whole body”. *Self-image* (I8) was negatively impacted, with comparisons to non-autistics: “it re-inforced that I will never be able to function at the same level as someone without ASD”. Self-hatred was evident, alongside hopelessness and a reduction in trusting self and self-confidence: “Strongly increased sense of hopelessness, loss of purpose in life and sense of self”. There was also a loss of *trusting others (cynicism)* (I9): “I became very untrusting of those I should trust (family and friends)”. A repeated subcategory, linked with recovery but more pertinent to impact, was *withdrawal – self isolation* (I10): “I know that I need to just exist in my own bubble for a while, and every second that I am not is a second that I feel worse”. Of most concern, was the frequent references to *suicide and suicidal ideation* (I11): “confirmed my inconsequentiality to society and existence”, “even attempting to kill myself a number of times”.

Major Category: Recovery

Recovery (strategies) was the last major category, with some experts referring to *tenacity – perseverance* (R1) required to survive: “I fought. Constantly... I never ever gave up”. A strong subcategory was the *space needed* (R2) to recover and replenish *energy*, often including reduced social interaction or escapism: “If I can shut out sensations and lie still for an hour, I

usually bounce back a bit but mostly I will need to be home for 2-4 days, the first day or two doing nothing but watch videos or something inert". Many commented on building new *self-knowledge* (R3) and new understanding of self-management strategies in guiding their recovery: "A big part of avoiding burnout is understanding your ability to cope at any given time. If ignored, repeatedly, then you will burnout and shutdown". There was *time needed* (R4), being "unfiltered" or spent on particular interests: "I need time to recharge myself away from people doing my projects". Many recovery strategies were identified, including *planning - pacing* (R5): "Learn to pace yourself and not do too much". Several commented on a *lack of appropriate support* (R6) making full recovery uncertain: "fear for my future when these events happen because no-one really gets it and no-one can really help". Some suggested they never returned to their previous levels of functioning with *incomplete recovery* (R7): "you don't know how much you will recover. This is quite scary if you are intelligent, not because intelligence is lost, but because it is harder to express that intelligence", "Believe this is how it will always be". Some mentioned a *unique recovery strategy* (R8) that was part of their experience: "I began a national support group", "got a nightshift job where I had minimal contact with people... I need 2-3 hours a day isolated to recharge".

Ancillary Category: Temporal Qualities

There were mixed reports on frequency. One expert reported they had only experienced a *one-off* (F1) burnout experience. Others referred to *intermittent* (F2) experiences: "Not the first time I have dealt with burnout, usually every 3-5 years", and several referred to *regular - ongoing* (F3) chronic burnout experiences, and others were still in recovery: "I still have times of burnout. Much of my life is in shutdown mode". Duration was also highly varied, from *days* –

hours (F4): “It varies. Sometimes, it can last all day, sometimes only a few hours or so” to reports of *weeks – months* (F5) or even years: “This one lasted for close to a year. It's hard to tell when it ended as it did so gradually”, “5 years or more”.

Ancillary Category: Differentiating from Depression

There were many *similarities* (C1) to depression and illnesses: “Frequent symptoms of depression and anxiety including sleep difficulties, lethargy, frustration, hopelessness”. The significant overlap and interrelatedness of depression and burnout meant for some it was difficult to pinpoint: “It can be hard to tell the difference”. *Differences* (C2) suggested included “symptoms such as sensory sensitivity and the need to isolate in order to recover is different to typical depression” and it “is more intense. A complete mind, body, soul thing – it’s everything”. There was suggestion that “depression is the side effect with burnout being the cause”.

Round 2

When experts reviewed the definition synthesised from the round 1 results, only one element did not meet the quantitative consensus criteria: “Time spent reintegrating with Self...” (see Table 2), and was subsequently modified to specify “in particular from chronic burnout”. Nine elements were flagged for revision based on qualitative comments received, flagged items are noted ^(B) in Table 2. The additional survey questions that interrogated the duration and frequency of burnout experiences did not lead to a clear resolution on these elements (see Table 3).

Table 2: Results of round 2 survey, excluding duration items

How much do you agree the following elements should be part of the definition of autistic burnout?	Number agree or higher (%)	Mean VAS rating (SD)	Revised based on results^A?
Fatigue from camouflaging or masking autistic traits	18 (81.8)	90.05 (12.83)	No
Overload of cognitive input ^B	15 (68.2)	82.00 (20.84)	Qual
Sensory environments unaccommodating to autistic sensitivities	15 (68.2)	80.59 (18.17)	No
Onset may be in combination with	18 (81.8)	65.45 (34.08)	No
Repeated unexpected changes ^B	18 (81.8)	80.91 (20.38)	Qual
Social environments unaccommodating to autistic sensitivities	17 (77.3)	86.68 (15.76)	No
Overload of work or activity demands	18 (81.8)	89.23 (15.03)	No
A severely debilitating condition	17 (77.3)	88.09 (15.45)	No
Significant mental and physical exhaustion	21 (95.5)	94.68 (10.58)	No
Social withdrawal ^B	20 (90.9)	91.73 (12.83)	Qual
With one or more of the following ^B	11 (50)	60.55 (38.89)	Qual
Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning	19 (86.4)	90.09 (18.77)	No
Confusions, difficulties with executive functioning, dissociative and/or fugue states	17 (77.3)	87.41 (13.63)	No
Increase in autistic traits (e.g. sensory sensitivity, repetitive or stimming behaviour, difficulties engaging or communication with others) ^B	18 (81.8)	91.91 (13.58)	Qual
The condition is not better explained by a psychiatric illness such as depression, psychosis, personality disorder, trauma- and stressor related disorders	14 (63.6)	72.00 (33.76)	No
Withdrawal from all social contact ^B	14 (63.6)	86.00 (19.50)	Qual
Withdrawal from externally imposed demands	19 (86.4)	93.59 (10.84)	No
Time spent re-regulating by stimming ^B	14 (63.6)	77.05 (27.81)	Qual

Time spent reintegrating with Self and external world via gradual passive to active engagement in activities e.g. moving from listening music to playing music... ^B	10 (45.5)	70.82 (31.69)	Quant.
A gradual return to daily activities and responsibilities	14 (63.6)	68.36 (33.29)	Qual
Differentiated from depressive episode. Autistic burnout has similarity to depression, though onset is primarily related to social interaction demands / masking fatigue, and overload.	15 (68.2)	75.45 (27.65)	No
Differentiated from mainstream burnout due to onset and manifestation not being solely related to employment	11 (50)	70.45 (33.61)	No
Differentiated from autistic 'meltdown' experiences due to severity and duration of exhaustion / fatigue ^B	16 (72.7)	84.18 (25.07)	Qual

^ARevised based on Qualitative (Qual) commentary or Quantitative (Quant) VAS results

^BElement that was revised for next round

Table 3: Results of round 2 survey duration items

Additional duration questions	<i>n</i> (%)
Shortest length of time you would consider to be an episode of burnout?	
Hours	2 (9.1)
1 day	7 (31.8)
2-3 days	2 (9.1)
4-6 days	4 (18.2)
A week	1 (4.5)
A fortnight or longer	5 (22.7)
Other (describe)	1 (4.5)
Experienced brief or intermittent episodes, prior to extended burnout?	
Yes	2 (9.1)
NA (only short episodes)	3 (13.6)
No (only experienced weeks or longer)	17 (77.3)

Round 3

All elements of the revised definition met the consensus endorsement criteria in round 3, with no additional qualitative data that suggested need to further refine the core definition (see Table 4 and Figure 3). Some qualitative data raised concepts of interest that were outside of scope; respecting participant expertise, these concepts are reported in Table 5. As consensus was met according to our established criteria in the third round of survey, and 19 of 21 experts (90%) agreed or strongly agreed that the definition described their experiences, theoretical saturation was achieved and a fourth round was not conducted.

Table 4: Results of round 3 survey

How much do you agree that the following are useful changes to the draft definition of autistic burnout?	Number agree or higher (%)	Mean VAS rating (SD)
adding 'interpersonal interactions'	19 (90.5)	91.81 (10.75)
added a definition for cognitive input, that it refers to 'thinking and mental processing'	18 (85.7)	84.19 (19.03)
added 'other additional stressors or changes'	18 (85.7)	88.52 (13.88)
added 'Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions'	18 (85.7)	90.33 (12.67)
changed 'social withdrawal' to 'interpersonal withdrawal'	20 (95.2)	94.05 (10.95)
changed to 'increased intensity of' autistic traits, and added 'and/or reduced capacity to camouflage/mask'	21 (100)	95.57 (6.34)
deleted the statement regarding duration, and added instead that 'Extended or chronic episodes of autistic burnout may be preceded by brief or intermittent episodes.'	15 (71.4)	82.14 (20.46)
added 'Whereas autistic meltdown can involve overpowering emotions, autistic burnout is more associated with emotional numbness'	13 (61.9)	78.29 (26.29)
added 'in particular from <u>chronic</u> burnout'	13 (61.9)	81.38 (19.34)
added 'and / or interpersonal'	18 (85.7)	92.29 (14.20)

added 'Down time spent on personal interests'	16 (76.2)	89.33 (14.49)
added 'routines'	14 (66.7)	84.43 (18.49)
Overall, how much do you agree that the second draft definition describes your experience(s) of autistic burnout?	19 (90.5)	89.14 (9.48)

Table 5: Further insights into the burnout experience identified by experts for future research

Insight
People may not realise the extent of burnout, as the person may have brief energy bursts usually related to positive stimulation, though overall be debilitated.
Burnout has an appearance of an inbuilt survival mechanism.
Without time to recover from burnout, removing external or self-imposed pressure to return to normal functioning too early, later burnouts or negative impacts on mental and physical health may be experienced.

PRELIMINARY DEFINED CRITERIA FOR AUTISTIC BURNOUT

Autistic Burnout is 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 changes. Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions. The following criteria must be met;

1. Significant mental and physical exhaustion
2. Interpersonal withdrawal.

With one or more of the following;

1. Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning.
2. Confusion, difficulties with executive function**, and/or dissociative states.
3. Increased intensity of autistic traits and/or reduced capacity to camouflage/mask e.g. increased sensory sensitivity, repetitive or stimming behaviour, difficulty engaging or communication with others.

The condition is not better explained by a psychiatric illness such as depression, psychosis, personality disorder, trauma- and stressor-related disorders.

Extended or chronic episodes of autistic burnout may be preceded by brief or intermittent episodes.

Differential diagnosis***;

Depressive Episode. Autistic burnout has similarity to depression, though onset is primarily related to social interaction demands / masking fatigue, and overload. In autistic burnout, social withdrawal is a recovery strategy. Behavioural activation treatment approaches are not recommended.

Mainstream (non-autistic) burnout. Mainstream burnout onset and manifestation is typically related solely to employment. In autistic burnout, social interaction / camouflaging and / or unsupportive sensory environments are elements of onset. In contrast, cynicism, if evident, is related to non-autistic people rather than employment. The impact may extend to changes in autistic traits and, for some, regression.

Autistic 'meltdown'. Autistic burnout differs from meltdown experiences due to severity and duration of the exhaustion or fatigue. Whereas autistic meltdown can involve overpowering emotions, autistic burnout is more associated with perceived emotional numbness.

*Cognitive input, refers to thinking and mental processing

**Please note, executive function refers to "the mental capacity to focus attention, to process information while completing other tasks, and to plan and remember instructions"

***Differential diagnosis is the process of differentiating between two or more conditions which share similar signs or symptoms.

Data available suggest recovery, in particular from chronic burnout, may be assisted by

1. Withdrawal from social and / or interpersonal contact and externally-imposed demands, potentially requiring convalescence during an in-patient admission.
2. Time spent on personal interests
3. Time spent re-regulating e.g. stimming
4. Time spent reintegrating with Self and external world via gradual passive to active engagement in activities e.g. moving from listening to music to playing music; from watching video gaming to playing video games
5. A gradual return to daily routines, activities and responsibilities.

Recovery may be incomplete in comparison to previous functional capacity.

Figure 3: Defined criteria for Autistic Burnout

Discussion

Autistic adults face daily stressors living in a neurotypical world. This accumulation of stress can trigger the debilitating condition, autistic burnout. Using GDM, which incorporates grounded theory with the Delphi method, experts reached a consensus on a definition for autistic burnout (see Figure 3). Autistic adults, as experts by experience, described a condition of autistic burnout that was not linked primarily to occupational stress and differed in severity and breadth of symptomology from literature reporting on non-autistic burnout. A large majority of experts agreed that the definition reached described their own burnout experience(s). A thick description (Geertz, 2017) and conceptual framework describing autistic burnout was developed from the open-ended survey results in round 1 (see Figure 2). Importantly, GDM enabled a rigorous member-checking process of the research team's interpretations.

On a surface level, autistic burnout shares commonalities with all three elements of non-autistic burnout described by Maslach (1986) – exhaustion, cynicism and work efficiency. Exhaustion is common in both, cynicism is more so directed towards interactions with neurotypical people as opposed to employment, and efficacy is more in relation to everyday functioning. Although there may be a withdrawal or distancing from occupation in non-autistic burnout, there is a more complete social isolation for many experiencing autistic burnout. Non-autistic burnout does not appear to include the cognitive disruption that many of our experts reported. Unique characteristics of autism appear to drive autistic burnout, particularly social interaction differences and sensory sensitivities. Where 'work engagement' (Leiter & Maslach, 2017) has

been suggested as a potential protective factor in non-autistic burnout, a concept of 'engagement', in relation to autistic individuals' ability to sustain in depth focus, may be both a protective factor and a risk factor for autistic burnout when that engagement is interrupted. There may be more commonality of autistic burnout with the revised understanding of non-autistic burnout emerging from the work of Tavella et al. (2020), which also includes social withdrawal and concentration problems within its core factor. More research will be needed to determine commonality and differences between autistic and non-autistic burnout, though we hypothesize unique stressors and treatment needs of autistic people will support a differentiation of these concepts.

Raymaker et al. (2020) arrived at their definition of autistic burnout, published after this study had commenced but prior to the manuscript development, using interview and social media data and a community-based participatory research process. Instead, we positioned autistic adults as experts by experience and co-produced a definition using GDM. Numerous similarities are evident particularly in the broader qualitative descriptions (e.g., chronic life stress, exhaustion, loss of functioning and reduced tolerance of stimuli) – but important differences exist in the definition produced (e.g., withdrawal, depersonalisation, masking). Several differences may stem from the presentations of the definition. Raymaker et al. (2020) based their definition on the (non-autistic) burnout definition in the ICD-11. Aiming to appeal to clinicians who might be supporting autistic adults, we chose to utilise the DSM-5 format, that allows a more detailed description of the condition, as well as differential diagnosis considerations. This is particularly important given (non-autistic) burnout has been criticised for its vague definition that cannot be differentiated from depression (Korczak et al., 2010). Similar

to the complex relationship between (non-autistic) burnout and depression (Maslach & Leiter, 2016), our participants suggested that autistic burnout is a cause of depression. A detailed description of autistic burnout is needed, particularly if determining comorbidity with depression, where the majority of criteria are in common depending on interpretation. For example, separating exhaustion from a continually depressed mood, and an inability to undertake activities from a diminished interest in them, or anhedonia. Differential diagnosis will be further complicated by the increased alexithymia experienced. We suspect that depression will be frequently comorbid with autistic burnout, though the current findings suggest that treatment recommendations should differ.

Of the seven differences between autistic burnout definitions to be noted, the first and primary deviation in definitions is the central role of withdrawal, which was only noted as a recovery strategy by Raymaker et al. (2020). Our experts consistently reported being compelled to withdraw and self-isolate as a key element of their burnout experience. Further work is needed to determine if this is simply a difference in interpretation of qualitative data, or a difference in understanding the core phenomena. Second, Raymaker et al. (2020) place “a mismatch of expectations and abilities” (p. 140) central to their definition. This concept is subsumed within our notes on onset relating to life stressors, though we would suggest that the mismatch is the environment within which the autistic person is expected to perform. The wording used in Raymaker et al. (2020) also is suggestive of a limitation of autistic people as opposed to a limitation of environmental conditions. ‘Treatment’ needs to address the environments within which the autistic person is expected to perform, not simply position the problem within the person. Third, masking and camouflaging, although being described as the “most prominent life

stressor” (p. 137, Raymaker et al., 2020), and recent literature highlighting its psychological impact (Cage & Troxell-Whitman, 2019; Hull et al., 2017), does not appear in their brief definition. Fourth, the Raymaker et al. (2020) definition mentions “loss of function” (p. 140). Given the substantial cognitive impact reported by some participants, we felt it important to note the dissociative states some experienced. Fifth, the increased sensory sensitivity described by our participants extended to a reduced ability to mask or increased intensity of autistic traits. Sixth, we identified *appropriate* support as being an element of recovery, whereas *adequate* support as described by Raymaker et al. (2020) does not capture those times when support persons, despite being well intentioned, can actually exacerbate the burnout experience or duration. Finally, where Raymaker et al. (2020) specified 3+ months duration, duration parameters from our experts were inconclusive.

It was a conscious decision by the research team to choose a clinical (DSM-5) format for drafting the definition as a means to build recognition and awareness amongst clinical professionals as well as awareness amongst the broader autistic and autism communities. Our results highlight that routine treatments for depression, such as cognitive behaviour therapy and behavioural activation, may be contra-indicated within autistic burnout, even though these conditions may co-exist. Our experts described the need for withdrawal and downtime for recovery, somewhat antithetic to behavioural activation. With cognitive overload being described as a key precursor of autistic burnout, cognitive-focused therapies could be counterproductive. There is a need, however, to ground these suggestions in experimental studies, and we believe there is a role for appropriate psychological support in recovery from autistic burnout. Autistic people daily face adversity in social interaction, as described in

Milton's (2012) double empathy problem, and underestimation of their self-awareness and ability to recognise the perspective of others as demonstrated by Heasman and Gillespie (2018). Overall, our results highlight the need to address social issues and sensory environments, to reduce stressors that can lead to autistic burnout or suicidal ideation for autistic adults.

Limitations

Given that no definition of autistic burnout existed when conducting the study, we simply recruited for autistics who had experienced autistic burnout, and deliberately did not provide description of what that might be. This meant the sample could potentially have included people who may not meet criteria for autistic burnout. Within our available resources and given the geographic spread of Australia we were not able to conduct clinical interviews with experts to identify and remove those who may be reporting on another condition, or to reconfirm formal autism diagnosis. Future research is needed that incorporates an element of structured clinical assessment, and measurement of co-occurring conditions, to validate the definition and differential diagnosis. Given heightened alexithymia (Kinnaird et al., 2019), proxy respondents may be of additional value, though the double empathy problem (Milton, 2012) and critiques of perspective taking raised by Heasman and Gillespie (2018) will need to be considered in analysis. Longitudinal research looking at coping strategies or other factors that mitigate or exacerbate autistic burnout would be beneficial, though a validated definition will be needed.

The majority of experts were Caucasian, well-educated and had full or part-time employment. Future research will need to validate the definition in a more diverse sample. Although there is slight female preponderance to the emotional exhaustion component in non-autistic burnout research (Purvanova & Muros, 2010), the greater number of female experts in our study is likely due to the higher female participation rates in online autism research (Arnold et al., 2019). Overall, the small sample and methodology do not allow any interpretation regards gender to be made, with future research required in this area. For inclusiveness, we allowed experts who only provided a partial response or no response in round 1 to participate in subsequent rounds, and experts were not linked across rounds to aid anonymity. This prevented the researchers developing an understanding of responses to later Delphi rounds based on individuals' experiences described in the first round. It would have also prevented the use of convergence or divergence metrics often employed in Delphi. Nevertheless, this is potentially a strength of our approach in that the definition developed was approved by some experts who were not involved in the initial round. Responses from our experts were highly heterogenous regarding the duration of autistic burnout, and the preliminary definition reached will need further validation particularly regarding duration criteria. Questions in the latter half of the round 1 survey probing elements of non-autistic burnout and depression may have influenced experts' responses and the definition constructed.

Finally, we believe the positioning of autistic people as experts and co-leaders of the research team together with clinician researchers was critical to understanding the clinical and existential experience of autistic burnout. The primacy of autistic voice ensured our understanding and interpretation of data were not skewed by neurotypical perspectives.

Conclusion

Autistic burnout appears to be a debilitating condition with onset linked to everyday stressors faced by autistic people in an unaccommodating world. The condition appears distinct from (non-autistic) burnout or depressive episodes. In common with (non-autistic) burnout, research is needed to establish further whether this condition might be a non-typical presentation of depression, chronic fatigue syndrome or another condition. Further research is needed to validate proposed definitions emerging within the literature. Consensus on definitions should be achieved prior to subsequent research such as the development of measurement tools, estimates of prevalence and identification of risk and protective factors. Clinicians need to be aware that treatments for depression may be contra-indicated. To ensure that the severity of this condition and its link to suicidality is not understated, more work on understanding and building awareness of autistic burnout is urgently needed.

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