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Autistic Burnout: Exploring Autistic Perspectives on Treatment Availability and Effectiveness

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Autistic Burnout: Exploring Autistic Perspectives on Treatment Availability and Effectiveness

by

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Abstract

Autistic burnout, characterised by chronic exhaustion, reduced tolerance to stimuli, and loss of executive function skills (Raymaker, et al., 2020) has severe consequences, including heightened mental and physical health problems, reduced capacity for independent living, decreased quality of life, and suicide attempts (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020). Although autistic burnout has been validated as a syndrome that is distinct from depression and occupational burnout (Higgins et al., 2021; Raymaker et al., 2020), it is unclear if mental health treatment providers are able to distinguish depression from autistic burnout (Rose, 2018). Yet, some treatments such as Cognitive Behavioural Therapy (CBT) and Behaviour Activation (BA) may be ineffective or contra-indicated (Higgins et al., 2021). Considering the limited literature on autistic burnout, the complexity of treating it, and the possible harm involved in providing a treatment that may be contraindicated, it is critical to gain a deeper understanding of this syndrome. This study aimed to explore Autistic experiences accessing treatment for autistic burnout and their perspectives on the effectiveness of the treatments that were offered to them. Eleven participants completed semi-structured interviews. Qualitative analysis was informed by an interpretive phenomenological analysis (IPA) framework using a hybrid inductive-deductive approach at a semantic level. Participants reported that clinicians often failed to identify autistic burnout and generally lacked knowledge of the condition. Misdiagnoses were common, leading to treatments that delayed recovery and exacerbated symptoms of autistic burnout. Participants described negative experiences accessing support, including lack of support services, which eroded their faith in the healthcare system. Potential effective treatments and supports were identified, primarily the need for rest and practical support. These findings highlight the need to raise awareness among clinicians about the nature of autistic burnout, the importance of collaborating with the Autistic client to develop a treatment plan, and the general need for more services for Autistic adults.

Autistic Burnout: Exploring Autistic Perspectives on Treatment Availability and Effectiveness

"Autistic burnout" has been discussed within the Autistic community for over 20 years (Mantzalas et al., 2023), yet the phenomenon has only recently captured the attention of researchers; therefore, academic and clinical literature on the topic is scarce. Searching for "autism" and "burnout" on research databases yields an abundance of articles on burnout associated with caring for Autistic people (Ardic, 2020; Boujut et al., 2017; Couderc et al., 2023), but found only six research studies explicitly focused on burnout in Autistic people (Arnold et al., 2023a, 2023b; Higgins et al., 2021; Mantzalas, Richdale, & Dissanayake, 2022; Mantzalas, Richdale, Adikari, et al., 2022; Raymaker et al., 2020). This dearth of academic literature on the subject is likely multifactorial.

Firstly, for decades Autistic individuals have expressed concerns that the efforts of autism charities are not aligned with Autistic priorities (Matthews, 2016). A report issued by the Office of Autism Research Coordination (OARC) and the Interagency Autism Coordinating Committee (IACC) (2011) stated that 30% (roughly $100 million (the largest portion of research funding)) was allocated towards the biological processes underlying autism; 17% (over $50 million) went towards identifying risk factors for autism. Comparatively, only 7% (nearly $23 million) went to researching services for Autistic people, while a mere 1% (almost $4 million) was assigned to studying lifespan issues (quality of life in adulthood, for example). This suggests that the emphasis of autism research remains predominantly on prevention or "curing" autism, despite widespread opposition to this approach among the Autistic community (Robbins, 2018). The recent publication on the *Future of Care and Clinical Research in Autism* (Lord et al., 2022) outlined recommendations for addressing the current needs of Autistic individuals over the next five years. Its research topics place emphasis on behavioural interventions, which does not reflect Autistic people's priorities (Roche et al., 2021). It seems that Autistic people are not being listened to, and Autistic priorities such as mental health support (Lipinski et al., 2022) remain low on the research funding agenda.

Secondly, autism research has historically been conducted on Autistic people, rather than with or by them (Jones, 2021), which limits the understanding of Autistic experiences and needs. This exclusionary approach has arguably led to misconceptions about Autistic behaviours and communication styles, often framing them as deficits. For example, the DSM-5 diagnostic criteria for autism spectrum disorder emphasises "persistent deficits in social communication and social interaction" (American Psychiatric Association, 2013), however, recent research demonstrates that Autistic people have a uniquely Autistic mode of communication, and when Autistic people are communicating amongst themselves, they do so with an efficiency that does not differ from allistics (non-Autistic people) (Crompton et al., 2020; Oates et al., 2024); thus challenging the idea that Autistic communication is inherently impaired. Unfortunately, failure to recognise Autistic behaviours as different, rather than deficient, has resulted in interventions that seek to suppress Autistic behaviour rather than support it (Rafiee & Khanjani, 2020). These interventions, such as behavioural therapies that aim to "normalise" Autistic behaviours to fit neurotypical standards (Autistic Self Advocacy Network, n.d.), are harmful (Sandoval-Norton & Shkedy, 2019; Shkedy et al., 2021) and masking, which is an inherent consequence of these therapies, can result in mental health problems among Autistic people (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Hull et al., 2017; Mandy, 2019), including PTSD (Kupferstein, 2018). Thankfully, more Autistic people are entering the field of autism research (Jones, 2021), and Autistic priorities, such as mental health and autistic burnout are starting to be addressed.

Autistic researcher, Dr. Raymaker et al. (2020), using thematic analysis and a participatory research approach, were the first to define autistic burnout as:

> . . . a syndrome conceptualised as resulting from chronic life stress and a mismatch of expectations and abilities without adequate support. It is characterised by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus. (p. 140)

Higgins et al. (2021), in collaboration with Autistic participants positioned as experts on autistic burnout, produced a second definition of autistic burnout using the Grounded Delphi Method (GDM). While Raymaker and colleagues (2020) conceptualised autistic burnout based on the ICD-11 definition of non-autistic burnout, the definition produced by Higgins et al. followed the DSM-5 format which allowed for a more complete description of the condition and includes differential diagnoses. Autistic experts defined autistic burnout as

> a severely debilitating condition with onset preceded by fatigue from camouflaging or masking[1] autistic traits, interpersonal interactions, an overload of cognitive input, a sensory environment unaccommodating to autistic sensitivities and/or other additional stressors or change.

Primary criteria included "*1. Significant mental and physical exhaustion"* and *"2. Interpersonal withdrawal"*, as well as reduced functioning, difficulties with executive function, and/or dissociative states, and increased intensity of Autistic traits (e.g., stimming behaviour and increased sensory sensitivity). Chronic life stress, exhaustion, loss of function and reduced tolerance to stimuli are present in both definitions; however, withdrawal, depersonalisation, and masking are included in Higgins et al.'s definition but are absent from the definition provided by

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[1] "Masking" is a term used by the Autistic community to describe the act of suppressing and hiding one's Autistic identity to appear "normal" and avoid discrimination (Milton & Sims, 2016).

Raymaker et al.. Mantzalas, Richdale, Adikari, et al. (2022b) examined social media posts to further investigate the construct of autistic burnout. Their findings validated the previous definitions of autistic burnout and suggest that autistic burnout is a chronic condition. Finally, Arnold et al. (2023a) investigated the content validity of the available definitions and found the definition provided by Higgins and colleagues offers a more complete description of autistic burnout. Therefore, the present study utilised the definition established by Higgins et al. as the operational definition of autistic burnout.

Autistic burnout has been validated as a syndrome that is distinct from depression and occupational burnout, with marked differences in aetiology and presentation (Raymaker, et al., 2020). The Job Demands-Resource (JD-R) model describes occupational burnout as a psychological state of exhaustion due to a lack of job resources which leads employees to withdraw from their work (Nadon, De Beer & Morin; 2022). While autistic and occupational burnout have a similar clinical presentation, their aetiology is notably different. Autistic burnout results from the demands of living in a world not built to accommodate Autistic needs and masking Autistic traits (Raymaker et al., 2020; Arnold et al., 2023a). Additionally, autistic burnout can lead to loss of skills, including thinking, executive functioning, and daily living skills, which do not always return once the period of burnout is over (Raymaker et al., 2020). In the case of occupational burnout, we see a pattern of reduced professional efficacy (Maslach & Leiter, 2016); however, loss of skills to the same degree as autistic burnout is absent from the literature. Furthermore, reduced tolerance to stimuli appears to be unique to autistic burnout, setting it apart from other forms of burnout or stress-related conditions. This phenomenon is marked by increased sensitivity to environmental stimuli such as light, touch, sound, and taste, which are already noted Autistic traits (American Psychiatric Association, 2013), but become overwhelming during periods of autistic burnout (Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020). Heightened sensory sensitivity can lead to significant discomfort and may exacerbate other symptoms of burnout, such as fatigue and emotional distress.

Depression is a common mood disorder characterised by a depressed mood, anhedonia (diminished interest or pleasure in activities), significant unintentional weight loss or gain, sleep disturbance, observable psychomotor changes (e.g., moving very slowly), fatigue, feelings of worthlessness, impaired ability to think, and recurrent thoughts of death (American Psychiatric Association, 2013). Sleep problems and anhedonia are core characteristics of depression, yet those themes were not present in Raymaker and colleagues' (2020) definition; furthermore, some participants with co-occurring depression noted differences between an autistic burnout episode and a depressive episode. Some Autistic people have argued that autistic burnout is the cause of their depression, suggesting that they are distinct conditions (Higgins et al., 2021). Further, the symptoms differ in that increased sensory sensitivity is not a criterion for depression, and withdrawal is a recovery strategy for autistic burnout (Higgins et al., 2021), whereas social isolation tends to worsen depressive symptoms (González-Sanguino et al., 2020). In addition to those previously mentioned, symptoms of autistic burnout may include increased presence of Autistic traits, a reduced ability to mask Autistic traits, and difficulty processing emotions; none of which are present in occupational burnout or depression. However, like depression and occupational burnout, if left untreated, autistic burnout may lead to suicide and suicidal ideation (Chesney et al., 2014; Higgins et al., 2021; Ulutasdemir et al., 2014).

In addition to the aforementioned direct effects, autistic burnout can result in serious indirect consequences. The cumulative impact of severe exhaustion, loss of skills, and impaired executive function and masking ability, compounded with protracted recovery period and possibility of incomplete recovery (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020), may partially explain the disproportionally high rates of unemployment seen in the Autistic population (Ki-Moon, 2015). Mantzalas et al. (2022) found that the effects of autistic burnout reportedly limited education and employment opportunities; with institutionalisation and homelessness also identified as consequences.

Anecdotal evidence suggests that mental health treatment providers are unable to distinguish depression from autistic burnout (Rose, 2018). Additionally, differentiating between autistic burnout and anxiety may also present challenges, as the conditions appear to share many features on the surface. For example, sudden increase in stimming behaviour brought on by autistic burnout may be interpreted as anxiety-induced restlessness, while being easily fatigued and having difficulties concentrating are features of both anxiety and autistic burnout. The interpersonal withdrawal seen in cases of autistic burnout may appear to be a result of social anxiety or depression, further complicating the process of differentiating between conditions. Many people with autistic burnout report a high rate of being misdiagnosed, with depression (40%) and anxiety (20%) being the most reported, along with bipolar disorder (8%) and borderline personality disorder (7%) (Arnold et al., 2023a). Treatments for depression, such as Cognitive Behaviour Therapy (CBT) and Behavioural Activation (BA), may be contra-indicated for autistic burnout (Higgins et al., 2021). Cognitive overload, a state of mental exhaustion arising when mental demands exceed one's capacity (*APA Dictionary of Psychology*, 2018), has been identified as a precursor to autistic burnout (Higgins et al., 2021; Raymaker et al., 2020). There has yet to be any research conducted on the impact of CBT on cognitive load; however, therapies focused on cognition may be counterproductive given the propensity for Autistics to become generally overloaded while experiencing burnout. Rest and withdrawal are necessary for recovery from autistic burnout (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020), however BA involves activity scheduling (i.e. increasing one's activity levels). Thus, it is the author's opinion that treating autistic burnout with these methods may be detrimental.

Previous research has consistently shown that a systemic lack of autism awareness results in frequent negative experiences within healthcare (Brede et al., 2022; Camm-Crosbie et al., 2019; Crane et al., 2019; Nicolaidis et al., 2015), employment (Davies et al., 2023), education (Hebron et al., 2017; National Autistic Society, 2023), and familial contexts (Lawoyin, 2022). It is believed that these experiences result in misdiagnoses, unreasonable expectations, and lack of support which contributes to the development and onset of autistic burnout (Raymaker et al., 2020; Mantzalas et al., 2021; Arnold et al., 2023a). The Autistic population displays a markedly elevated prevalence of co-occurring mental health conditions compared to the general population (Lever & Geurts, 2016). However, they frequently report negative experiences within the healthcare system and bear a profound mistrust of healthcare providers due to lack of autism training, negative attitudes and stereotypes about autism, previous misdiagnoses, unaccommodating environments, and communication differences, (Brede et al., 2022; Camm-Crosbie et al., 2019; Lewis, 2017; Nicolaidis et al., 2015). These factors collectively heighten the burden carried by Autistic individuals and plausibly contributes to the development and exacerbation of autistic burnout.

Given the potentially debilitating nature of the symptoms of autistic burnout, the seriousness of the potential consequences, the limited available literature on the condition, and the potential harms of providing treatments that may be contraindicated, it is critical to gain a better understanding of this phenomenon. Additionally, prioritising recognition, understanding, and support for autistic burnout is a leading concern for Autistic people (Rose, 2018). This study is the first to qualitatively explore Autistic perspectives on accessing mental health support for autistic burnout. The proposed research aims to enhance the understanding of the Autistic experience in accessing treatment for autistic burnout in the hopes that this information will allow us to further improve awareness of autistic burnout in clinical settings and promote better mental health outcomes for Autistic individuals.

Method

Background and Perspective of the Researchers

The first author approached the research design and analysis with a background of being a late-diagnosed Autistic with previous experience of seeking professional support for autistic burnout. The remaining authors reviewed the analysis with the experience of being Psychologists with training and knowledge of mental health experience assessing and treating Autistic adults.

Recent research on autistic burnout (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020) and Autistic experiences accessing healthcare (Brede et al., 2022; Camm-Crosbie et al., 2019; Crane et al., 2019) provided critical themes that were used to structure data collection and served as the deductive component of the current study.

Research Design

Qualitative analysis informed by an Interpretive Phenomenological Analysis (IPA) framework was employed to generate and refine themes as the data were collected (Smith et al., 2022). IPA was deemed a suitable methodology exploring Autistic experiences accessing treatment for autistic burnout for several reasons. The fundamental goal of IPA is the detailed examination of individual experience. This orientation towards experience aligns well with the study’s aim of understanding the unique experiences of Autistic individuals. IPA allows for a deep exploration of participants lived experiences, which is crucial for understanding the experience of autistic burnout and how Autistic individuals navigate and interpret their experiences accessing treatment. Furthermore, IPA affords the flexibility to accommodate a range of data collection methods. This study offered participants three modalities to communicate with the researchers, therefore a flexible methodology was essential. Lastly, IPA encourages reflexivity, which involves researchers examining their own experiences and how these may influence the research process. Given the first author’s personal experience with accessing treatment for autistic burnout, this aspect of IPA was vital in ensuring that the interpretations were grounded in the participants experiences. Finally, the methodology’s sensitivity to complex experiences made it well suited for exploring the multi-faceted nature of autistic burnout.

Researchers used a hybrid inductive-deductive approach to analysis. Specifically, the inductive approach was used to characterise participants’ experiences; however, given that previous research had already characterised autistic burnout and described possible contra-indications for therapies such as CBT and BA (Higgins et al., 2021), a deductive methodology was also utilised. Analysis was conducted using a semantic approach, where only explicit content was analysed. This was done in recognition that Autistic people use language very precisely and express frustration when others try to extrapolate implied meaning from their words that are not there (Kelliher, 2022).

Participants

Prior to recruitment, approval was obtained from the institutions research ethics board. Nonprobability purposive sampling was utilised to target the recruitment of Autistic individuals who had experience with autistic burnout. Attempts were made to capture a diverse range of experiences through advertising the study on various social media platforms, allowing for global responses. Participants were self-selected by responding to advertisements on the social media platforms Facebook, Instagram, and Reddit. Facebook advertisements were posted in groups for Autistic people, and the Instagram advertisement was posted via the undergraduate researcher's professional Instagram account under #AutisticBurnout, #Autism, #ActuallyAutistic. No incentives were provided for participation in the study. Recruitment was stopped after 12 participants were interviewed, as similar sample sizes have proven sufficient for data saturation in previous IPA research (Smith et al., 2022).

To be included in the study, adults had to (1) have an autism diagnosis or self-identify as Autistic, (2) be currently experiencing or have previous experience with autistic burnout, (3) be currently seeking or have previously sought help for autistic burnout from a professional in the mental health field, (4) have the ability to give independent informed consent, and (5) be over the age of 18 years old. Verification of autism diagnosis was not undertaken due to limited resource availability and in consideration of the numerous barriers to diagnosis that people face (Bargiela et al., 2016; Freeman & Paradis, 2023; Garel & Garel, 2018; Lewis, 2017; Murphy et al., 2023a, 2023b; Weitlauf et al., 2024).

Twelve Autistic adults completed the interviews; one participant was removed from the study due to insufficient data, leaving 11 participants (91.6%) in total. Participants resided in Canada (n = 5), United States of America (n = 5), and one participant split their time between Vietnam and South Africa. Most participants were in the age bracket of 25-34 years old (n = 6);

two participants were between 55-64 years old, one participant was between 35-44 years old, one participant was between 18-24 years old, and one participant was over the age of 65. Most participants identified as women (n = 6), with smaller proportions of men (n = 2), non-binary (n = 1), and grey gender (n = 1). One participant did not disclose their gender. Most participants had a formal diagnosis of autism (n = 7), while others were self-diagnosed (n = 4). Of the 11 participants, seven were experiencing autistic burnout at the time of the study and three had experienced it previously. Every participant had obtained formal higher education at a range of levels: some university (but no degree) (n = 1), bachelor's degree (n = 3), graduate degree (n = 3), and master's degree (n = 4). Finally, most participants completed the online survey (n = 4) or interview (n = 4), with the remainder choosing to complete the email survey (n = 3).

Procedure

Consent

A link on the advertisement directed interested individuals to an online survey, where they were provided with information about the study and consent forms. After reviewing the information, prospective participants were asked to provide their consent to participate in the study. Interview questions were shared with participants who selected the video interview option prior to the interview, thus enabling them to prepare their answers prior to the interview. It was not necessary for the participants to prepare answers in advance; however, having the option to do so could potentially alleviate any anxiety they felt about going into an unfamiliar situation, such as an interview.

Data Collection

Eligible participants were asked for information about their demographics, including their gender, ethnicity, and primary country of residence. Participants were also asked for their preferred mode of participation: (1) Online Survey, (2) Online video interview, or (3) Email. Three modes of participation were offered as research suggests that Autistic research participants benefit from different communication modalities, with email being the preferred method for research purposes (Howard & Sedgwick, 2021).

Participants engaged in an email survey, online survey, or a semi-structured interview, with questions designed to garner information about their experiences accessing professional support for autistic burnout. The questions were open-ended, designed to encourage personal reflection on their experiences, and aligned with the aims of the study. Participants were asked broadly about their experience of autistic burnout (e.g., "*Describe what Autistic burnout is like for you"*). More specific questions were asked about their perception of their treatment providers' knowledge of autistic burnout and the treatments that were offered to them (e.g., "*How knowledgeable did your treatment provider seem about Autistic burnout?"* and *"What treatments were offered or suggested to you?"*). A comprehensive list of the interview and survey questions can be found in the appendix. Participants were prompted to "answer the questions in as much detail as possible" to "take the researchers there" and to provide sufficient data for analysis.

Participants who selected the survey option continued to answer the interview questions through long-response text on an online survey program. At the end of the questions, they were given the option to provide their email to allow the researcher to reach out with follow-up questions if needed. Following this, they were directed to a debrief form containing a summary of the study and contact details of the researchers and counselling services, should they need them.

Verbal consent to begin audio recording for transcription purposes was obtained at the start of the interview. Interviews were held for 73 – 119 minutes, with an average interview time of 98 minutes. During the interview, participants were asked if there were any questions that the researcher didn’t ask, but that they felt would be beneficial to the study. One participant suggested adding the question, *“outside of professionals, where else have you turned to for support?”* which was then included in the question list for the remainder of the participants.

At the end of the interview, participants were asked if they would like to receive a copy of their transcript for their review and editing prior to analysis. If the participants agreed, they were asked to provide their email address. After the interview, participants were debriefed and asked if they would like a copy of the debrief form emailed to them. If the participant agreed, they provided their email address and received a copy shortly after. Verbatim transcriptions were then sent back to the appropriate participants via password-protected emails, with the password to access the document sent in a separate email.

Participants who selected the email option were asked to provide their email address and indicate their consent to use email for potential follow-up questions if necessary. They were then sent a copy of the interview questions, and participants emailed their responses back to the researcher. Extra precautions were taken to ensure the information being relayed over email was secure. Emails from the researcher were password-protected, and participants were encouraged to password-protect their response documents. All responses were anonymized within 48 hours upon receipt, and the original email was deleted.

Data Reduction and Analysis

Analysis began with data cleaning, during which each transcript was thoroughly checked against the audio recording for accuracy. Any identifying information was removed from the transcript. Thematic analysis was informed by IPA framework (Smith et al., 2022) using a hybrid inductive-deductive approach to analysis on a semantic level. Open coding was conducted in parallel to the IPA process. Themes were extracted from each data source using open coding (Williams & Moser, 2019), then compared and connected across the entire corpus to establish categories and themes. An initial inductive code list was generated from representative data sources, and a deductive code list was established based on the available published literature. The first author then reviewed the entire corpus using the established code set, identified any additional codes to be added, and refined the final code list.

Following data cleaning, the IPA process was initiated. First, the semantic content was explored for each dataset and a comprehensive set of notes was produced which reflected matters of significance to each participant. Secondly, experiential statements were developed to reduce the volume of detail while maintaining the complexity of each participant's experience. Thirdly, associations were made between experiential statements, which served as the foundation for creating clusters of themes. These clusters of experiential themes were then developed into Personal Experiential Themes (PETs). Finally, cross-case analysis was performed on the PETs to identify similarities and differences. These were then organised into clusters, which were termed Group Experiential Themes (GETs). Core, major, and subthemes were identified. Core themes were those themes that were present in and interconnected to nearly every other major theme in the analysis. Subthemes were identified from grouping similar PETs and major themes reflected the GETs.

Data Verification

The decision was made to allow participants to review and edit their transcripts in recognition of the difficulties that some Autistic people face with spoken language; this ensured that researchers would only use the information that the participants intended to convey. Only one interview participant wished to review their transcript, and they returned their edited transcript with further elaborations. Three email participants were sent emails with follow up questions, however only one responded with clarifications. The analysis went through multiple iterations to ensure a comprehensive analysis. The full theme list was sent to all members of the research team, who were asked whether the codes reflected their interpretations as clinicians. Based on this, some codes were rephrased.

Results

Analysis of qualitative data generated a description of autistic burnout delineating core, major, and sub-themes (see Table 1). The core theme was *energy*, which permeated through the major and sub-themes. The major themes were *onset*, *impact*, *temporal qualities*, and *differentiating from depression and other conditions*, indicating that these aspects are important to a thorough definition of autistic burnout. Additionally, the thematic analysis of participant descriptions regarding accessing support for autistic burnout facilitated the identification of four major themes and numerus sub-themes, which highlight the complexities and multifaceted nature of the challenges faced by Autistic individuals seeking support for autistic burnout. Treatments perceived as effective and ineffective by participants were also discerned.

Table 1

Participant Descriptions of Autistic burnout: Major Themes and Subthemes

Major Theme	**(Code) Subtheme**
Energy	(E1) Retrospective Identification
	(E2) Supportive Environments
	(E3) Lack of Control
	(E4) Masking

Major Theme	**(Code) Subtheme**
Onset	(O1) Social Interaction
	(O2) Misunderstanding of/by Others
	(O3) Unexpected Change/Life Transitions
	(O4) Emotional Overwhelm
	(O5) Cognitive Overload/Overwhelm
	(O6) Sensory Overload/Overwhelm
	(O7) Work Demands
	(O8) Co-Occurrences Trigger Burnout
Impact	(I1) Severity Varies
	(I2) Increased Autistic Traits
	(I2a) Difficulties with Communication
	(I2b) Increased Sensory Sensitivities
	(I2c) Need for Sameness
	(I2d) Stimming
	(I3) Reduced Functional Capacity
	(I3a) Occupational/academic
	(I3b) Daily Living
	(I3c) Cognitive
	(I3d) Emotional/Behavioural
	(I3e) Social
	(I4) Withdrawal
	(I5) Exhaustion

Major Theme	**(Code) Subtheme**
	(I6) Physical complaints
	(I7) Negative Descriptions
	(I8) Co-Occurring Conditions
	(I9) Self-Image
	(I10) Suicide/Suicidal Ideation
Temporal Qualities	(T1) Early Onset
	(T2) Chronic
	(T3) Months-Years
	(T4) Days-Weeks
	(T5) Duration Varies
Differentiating from Depression & Other Conditions	(D1) Depression
	(D2) ADHD
	(D3) Occupational Burnout
	(D4) Fibromyalgia
	(D5) Concussion

Describing Autistic burnout

The five major themes identified as important to a thorough description of autistic burnout were *energy* (core theme), *onset, impact, temporal qualities,* and *differentiating from depression and other conditions.*

Core Theme: Energy

Energy emerged as an overarching theme, wherein autistic burnout was intricately linked to the participants' "energy bank," which refers to the mental, physical, and emotional resources required to navigate daily life. For example, one participant stated: "it's kind of like an energy budget." Within the core theme of *energy*, subthemes of *retrospective identification, supportive environments, lack of control,* and *masking* were identified, which either contributed to or depleted the participants' energy reserves. *Energy* constituted the crux of their encounters with autistic burnout and was intricately interwoven with its *onset, impact,* and *recovery*.

For most participants, their experience with autistic burnout was *identified retrospectively* after being late diagnosed/identified as Autistic, i.e., they were unaware that they were experiencing autistic burnout at the time of their struggles. One participant stated: "Now that I understand it is autistic burnout in hindsight, 'cause I was kind of a late diagnosis." Delayed identification of autistic burnout depleted participants energy levels due to the lack of awareness about the condition and appropriate strategies for managing it. Without the label of autistic burnout, participants and healthcare providers often misinterpreted their symptoms as depression, leading them to push through their difficulties. One participant explained they were "forcing myself through what I thought was like depression."

Participants shared that a *supportive environment* (E2) had a positive impact on their energy levels thereby mitigating their experience of burnout, for example, "Before living on my own, I had a very structured life where I didn't have to prepare my own meals or take care of lots of chores….I didn't notice much burnout until after I started living on my own," whereas an unsupportive environment had a negative impact on energy, making burnout more likely: "[autistic] burnout has a lot to do with not having support to prevent it." Similarly, participants reported a *lack of control* (E3) over their environment, schedules, sensory input, and social demands contributed to their experience of autistic burnout:

> it depends for me on whether I'm employed, like that external loss of autonomy from having to be somewhere and do something... Up to 40 hours a week, every week, day in day out ... Every couple of years I'll get close to burnout and then if I'm not careful I slip into it.

In contrast,

> I think that's why I don't go into burnout when I'm not working. It's not that I'm suddenly able to deal with all the stimulus, but it's just that I can manage my own threshold better without like a boss expressing, you know, "do the things."

This participant highlights that when they have autonomy over their schedule, they're able to manage their energy more effectively, therefore preventing burnout episodes.

Masking (E4) is the act of hiding one's Autistic traits. Participants explained that *masking* drains energy resources which impacted their experience of autistic burnout:

> [masking] begins to be more and more difficult and it feels like a self-betrayal. The more that I do that the more that I feel burnt out and eventually I'll just have the threshold where I can't function anymore so then I'll just be kind of laid up in bed for a while.

Though the burden of *masking* is not always visible to others. For example, one participant voiced: "I plan things very well and then I execute them and then that does well and then people think you are a high achiever, and you are, you do really well, but its…do you know what that took?" The subtheme of *masking* was also evident in two other major themes: *onset* and *impact*: "every two-to-six years, the masking catches up to me and I have a serious burnout that can last one-to-two years." Continuous withdrawal of energy without the ability to sufficiently replenish culminates in a state of autistic burnout, ultimately leading to the need to withdraw socially to recover.

Major Theme: Onset

Social interaction (O1) was described by participants as precipitating autistic burnout: “extended social situations lead to burnout”, as well as *misunderstanding by & of others* (O2): “I am currently in a burnout due to being harassed (for common autism traits) at my past workplace” and “It’s really trauma from growing up neurodivergent and no one really seeing that and just thinking I was being lazy and pushing me.” *Unexpected change & life transitions* (O3) were cited by many participants as a catalyst for autistic burnout: “change is a huge trigger,” though the changes do not always have to be negative in their nature: “even positive changes make me feel anxious and disoriented.” *Emotional overload & overwhelm* (O4) can also trigger burnout: “I get more burnt out when I’m emotionally upset,” as well as *cognitive overload & overwhelm*: “that makes it very difficult to function because everything is overwhelming.” Overload can also be due to *sensory overwhelm & overload*: “we take in so much more stimuli than other people…of course you’re going to break down if all that’s flooding into you.” Most participants referred to *work demands* (O6) as contributing to burnout: “when my work life becomes more stressful, I am more susceptible to burnout.” Finally, autistic burnout being triggered by co-occurring health condition flare-ups was described in *co-occurrences trigger burnout* (O8): “the burnout is made worse by the physical health stuff.” Onset of Autistic burnout was succinctly described by one participant: “that's what I think burnout is, operating at a level that's not your level of sustainable output. It's too high, therefore the systems eventually overloads.”

Major Theme: Impact

Participants found that the *severity varies* (I1) regarding autistic burnout, “it’s like a wave, it’s up and down,” with most participants describing *increased Autistic traits* (I2): “This experience of autistic burnout made my Autistic traits way more noticeable.” For example, *difficulties with communication* (I2a): “I can go semi-verbal,” and *increased sensory sensitivities* (I2b):

> The pair of pants that I wore at the beginning of this job was fine. Then in burnout, it’s like I will burn those pants. I can’t stand the way they feel. Like I’ve seriously had days in burnout where I’m like, this is a no clothes day, I can’t stand the feeling of fabric on my skin.

Some also described an intense need for *sameness* (I2c): “I could not change what I eat [*sic*]…it had to be the exact same thing every single day,” and *stimming* (I2d): “I was publicly stimming.”

Every participant commented on having a *reduced functional capacity* (I3): “I became progressively less functional.” *Reduced functional capacity* was observed across a range of areas, including *occupational & academic* (I3a): “my job put me on EI [employment insurance] because I kept calling in sick for work,” *daily living* (I3b): “daily tasks range from difficult to impossible,” and *cognitive* (I3c): “the biggest sign of burnout for me is like when the executive functioning starts fizzling out.” One person also experienced dissociation: “my own perception of my mental state was mismatched by my voice which I could hear was crying…it felt like a microphone effect…I couldn’t understand why my voice was crying.” Participants *emotional & behavioural* (I3d) functioning was also affected: “I would hide in closets in the house, or would be unresponsive for days, and I would scream at them for having their voices or TV too loud,” as well as their *social* (I3e) capacities: “I struggle to interact with those in my household.”

Most participants described interpersonal *withdrawal* (I4), also recognised as a recovery strategy, as an impact of Autistic burnout: “I don’t see anyone outside my household for months.” Many participants described feelings of intense *exhaustion* (I5): “Number one is feeling exhausted. Not just physically exhausted….but just exhausted. Physically exhausted as well…like, my soul feels exhausted. Like, breathing feels exhausting. Thinking feels exhausting.” Multiple participants also complained of increased *physical complaints* (I6) during periods of autistic burnout: “I was having these really horrible headaches, migraines, feeling just on the verge of tears.” *Negative descriptions* (I7) were common: “My life was spiralling out of control; “it was a terrifying experience.”

Some participants mentioned *co-occurring conditions* (I8) flaring up due to autistic burnout, “my CNS [Central Nervous System] related co-occurring conditions … are completely intertwined with when I experience burnout. These all get exacerbated as a result of burnout.” New conditions were also cited as emerging from autistic burnout: “bed sores, insomnia, binge-eating disorder, worsened physical ailments from stress, chronic hives, GERD [Gastroesophageal Reflux Disease].” *Self-image* (I9) was negatively impacted for many participants: “You feel so bad about yourself because I already had a very easy paced, low demand life, and then…now we have to ease even more demands,” with some feeling “shame for lowered productivity.” Finally, and quite worryingly, were the multiple mentions of *suicide & suicidal ideation* (I10): “the demands of living became too much in general….I started to have some intrusive thoughts and suicidal ideation;” “I got on a cruise to the Caribbean with the intention of drowning myself.”

Most participants described an *early onset* (T1) of autistic burnout, usually occurring in their teen years, though one participant had his first experience in elementary: “I was about 8 years old." Every participant described their burnout as a *chronic* (T2) condition: "much of my burnout is chronic and ongoing," with many describing it lasting for *months-to-years* (T3): "It was 6 years I was dangling in a level of burnout;" though some participants found that their burnout lasted *days-to-weeks* (T4): "I experience a period of extreme burnout maybe once every couple of weeks and it lasts a couple of days." However, most participants found that the *duration varies* (T5): "Sometimes it only lasts a weekend. Other times it lasts for 1-2 years." The range of temporal qualities of autistic burnout are illustrated in Table 2.

Table 2

Temporal Qualities of Autistic burnout

Subtheme	**N (%)**
Early Onset	7 (64)
Days – Weeks	5 (45)
Months – Years	5 (45)
Duration Varies	7 (64)
Chronic	11 (100)
Retrospective Identification	5 (45)

Auxiliary Theme: Differentiating From Depression and Other Conditions

There were many similarities to *depression* (D1): "I become progressively less functional (not taking care of hygiene, losing my sleep schedule, inability to concentrate at work, inability to complete necessary tasks like paying bills or maintaining cars etc.)." The symptom overlap with depression made it difficult for some participants to tell the difference: "I thought it might have been depression, but it wasn't." Some participants articulated differences such as being able to identify a cause of their low mood:

> It was always viewed as like, this is just your depression, like you just have major depressive disorder. So, you're just gonna have all these depressive episodes for no reason. And now, looking back, I'm like how much of it was for no reason and how much of it was for a reason, and that also, like helps often for me, assess with clients and myself, like what feels like depression versus burnout where like usually there is some precursor, some things that are going on that you don't have control over to a certain degree that end up stacking up. And then you, I implode usually.

Additional distinctions included absence of emotional symptoms of depression such as low mood: "I was told it was depression / anxiety, but I wasn't sad about anything or even felt life was worthless."

One participant mentioned similarities to *Attention Deficit Hyperactivity Disorder (ADHD*) (D2): "For the longest time I just thought I had ADHD because…executive functioning issues, this is probably just ADHD." And while autistic burnout shares similarities to *occupational burnout* (D3) such as *exhaustion,* "Feeling really tired and needing to take days off," there are notable differences: "what made me begin to put together pieces of my experience as being "autistic burnout" and not just "occupational burnout" had to do with the intensity, frequency, and duration of meltdowns." Autistic burnout was also felt to be more intense than occupational burnout, "[autistic] burnout, which is regular burnout plus just a bit more to make it worse," with greater impacts: "the cost is much greater and much more intense for brains that experience more of it." Autistic burnout was also compared to *fibromyalgia* (D4) with one participant noting similarities in symptoms: "noise and light sensitivities, sensitive to stress, cognitive dysfunction, chronic pain and fatigue, emotional sensitivity." Another participant compared autistic burnout to a *concussion* (D5): "They have many similarities in that overstimulation from sensory inputs can trigger issues. Irritability, fatigue and similar symptoms exist."

Comparison to Professional Definitions

Major Theme: No Professional Explanation

The overwhelming majority of participants (all but one) reported that their healthcare providers were either unable or unwilling to define or explain autistic burnout. Consequently, this led to the emergence of a major theme, *no definition given*: "my treatment provider did not explain autistic burnout to me." Furthermore, although one participant indicated that their current healthcare provider had provided an explanation of autistic burnout, they did not provide insights into this definition. The participant also noted that all previous providers, like the experiences of other participants, had failed to describe autistic burnout. The absence of definitions by professionals meant that it was not possible to compare descriptions of autistic burnout between treating professionals and the participants experience. A breakdown of the major and subthemes related to accessing treatment can be found in table 3.

Table 3

Experiences Accessing Treatment: Core Themes and Sub Themes

Major Theme	**(Code) Subtheme**
No Professional Explanation	N/A
Need for Professional Support	N/A
Barriers to Support	(S1) Lack of Support & Resources (S2) Lack of Autism Knowledge

Major Theme	**(Code) Subtheme**
	(S3) Stereotypes
	(S3a) Age
	(S3b) Gender
	(S3c) Too Intelligent
	(S3d) Too Empathetic
	(S3e) Too Functional
	(S4) Dismissed by Healthcare Providers
	(S5) Lack of Empathy
	(S6) Misdiagnosed
	(S7) Complex Healthcare System
	(S8) Environmental Barriers
Impact	(M3) Patient Advocacy
	(M1) Feeling Misunderstood
	(M2) Importance of Knowledgeable Therapist
	(M4) Lack of Trust in Healthcare System
	(M5) Alternative Avenues to Support
	(M5a) Autistic Community
	(M5b) Leveraging Co-Occurs
Ineffective Treatment	(R1) Psychotherapies
	(R1a) Cognitive Behaviour Therapy
	(R1b) Dialectical Behaviour Therapy

Major Theme	**(Code) Subtheme**
	(R1c) Behavioural Activation
	(R1d) PTSD Group Therapy
	(R1e) Skills Group
	(R2) Medication
	(R3) Neuronormative Approaches
	(R4) Harm from Ineffective Therapies
Effective Treatment	(R5) Psychotherapeutic Approaches
	(R5a) Acceptance Commitment Therapy
	(R5b) Eye-Movement Desensitisation & Reprocessing
	(R5c) Internal Family Systems
	(R5d) Somatic Therapies
	(R5e) Interpersonal Effectiveness
	(R6) Self-Regulation Techniques
	(R7) Non-psychological approaches
	(R8) Basic Supports
Self-Management	(Y1) Time
	(Y2) Space
	(Y3) Rest
	(Y4) Planning & Pacing
	(Y5) Self-Knowledge
	(Y6) Boundaries

Major Theme	(Code) Subtheme
	(Y7) Special Interests
	(Y8) Experiencing Joy
	(Y9) Distraction
	(Y10) Unmasking
	(Y11) Nutrition & Movement
	(Y12) Environmental Control
	(Y13) Supportive Environment
	(Y14) Lack of Support
	(Y15) Sensory Considerations
	(Y16) Animals
	(Y17) Incomplete Recovery

Experiences Accessing Support

Major Theme: Need for Professional Support

Every participant expressed a *need for professional support: "*I wanted to get help for the transition to work that was already impacting my daily functioning and growing support needs," with multiple participants going so far as to say that without it, the consequences may be catastrophic: "we can ruin our lives in an instant if we are unlucky enough to have no support systems," or even more concerningly, fatal: "If I didn't have the support I have with therapy, I don't know if I would be here. I might be dead honestly, years ago."

Major Theme: Barriers to Support

Despite the overwhelming need for support, every participant complained of *lack of support & resources* (S1): “So far we haven’t found anyone able to help.” Furthermore, autism resources were often inappropriate: “so much of what I’ve seen is focused on behaviourism and children, neither of which is very helpful for my situation,” which left participants feeling desperate, “I have begged for help for 8 years.” Every participant described multiple *barriers to support,* including a systemic and pervasive *lack of Autism knowledge* (S2) among healthcare professionals: “my impression is that we are at the level of not understanding autism itself, leave alone any way in which being Autistic impacts other things (such as burnout).”

Perceptions of lack of autism knowledge was apparent in the frequent descriptions of use of *stereotypes* (S3) among healthcare providers. *Stereotypes* about Autism included *age* (S3a): “people think Autism [sic] is only something that affects children,” *gender* (S3b): “if someone does consider that an adult can have Autism [sic], then assume that only adult males are Autistic,” being *too intelligent* (S3c): “If you were someone, especially who didn’t have any intellectual issues, and academically you’re doing well … autism is not really the route that they go,” *too empathetic* (S3d): “a behavior [sic] tech pushed me to join groups. When I told him I'm extremely empathetic and therefore have trouble in groups, he said, “how can you be extremely empathetic if you're Autistic?” Finally, participants were told they were *too functional* (S3e) to be Autistic:

> there are so many professionals who believe that adults can't be Autistic in the first place, or if they are like, it is a very specific presentation... They're not looking for somebody who, you know, has for whatever reason this profession or this appearance or this education level... They have a very narrow definition of who is Autistic.

Most participants had their concerns about autistic burnout *dismissed* (S4): “They have dismissed me in clinics, their offices and in hospital,” with many describing *stereotypes* as the foundation for dismissal: “I was dismissed because I could speak to my doctor” (some people believe that you can only be Autistic if you’re non-verbal). Many participants described being disbelieved by their healthcare provider when they disclosed their autism diagnosis: “even though I had a document stating my diagnosis, they didn't seem to believe it.” Similar to *dismissed,* multiple participants felt that their healthcare provider displayed a *lack of empathy* (S5): “I was gaslit and mocked by a doctor and literally had my lab results thrown in my face “Told you are fine, just crazy, get out my office.””

Additionally, while each participant was experiencing autistic burnout when they sought professional help, many felt that they had been *misdiagnosed* (S6) with other conditions, with depression being the most common: “it was always viewed as like, this is just your depression, like you just have major depressive disorder. So, you're just gonna have all these depressive episodes for no reason,” followed by anxiety: “My GP diagnosed me with anxiety,” and borderline personality disorder: “I was horribly misdiagnosed with borderline personality disorder.” One participant was also diagnosed with avoidant personality disorder: “He decided I had avoidant personality disorder.” Lacking awareness of one’s Autistic identity can have negative consequences: “Not having a diagnosis can lead to that suicidality…That’s why they diagnosed me with BPD,” as does misdiagnosis: “I think they thought everything was rooting from depression, low-self esteem, maybe not prioritizing things…it made me feel worse about myself.” Many participants stressed the importance of an accurate diagnosis on treatment effectiveness: “That just proves how important correct diagnosis is. If the diagnosis is not the correct one then the treatment will not help you in any way,” and preventing burnout: “After I got my official diagnosis and demands being lifted…and suggestions of changes at home…I won't say I reached that deep level of autistic burnout ever since."

Other barriers to support include *complex healthcare systems* (S7): "navigating the mental health system is extremely difficult, especially when you are already struggling," and *environmental barriers* (S8) can make it difficult to access support:

> healthcare providers in general don't do much to accommodate Autistic needs. For instance, the inability to book appointments online. It is well documented that Autistic individuals find phone calls difficult and phone booking is a noted barrier to healthcare access. I am no exception to this. Phone calls cause me extreme anxiety, it can take me hours to get up the courage to make a call. Auditory processing issues make it difficult to understand someone without the visual cues of lip reading. Accents are especially difficult.

The environment may also exacerbate distress when seeking crisis support:

> So many things that would make the burnout worse were more present in the hospital. The lighting was harsh. It was noisy. I was pressured into attending group therapy, even though I would go back to my room and meltdown each time. It was always too hot. It smelled bad.

Major Theme: Impact

The experience of accessing care had multiple impacts on participants, with many feeling *misunderstood* (M1) by their healthcare provider: "I think it's pretty clear how I feel by now. Not at all understood." Linked to the concept of *misunderstood,* several participants commented on the *importance of knowledgeable therapists* (M2):

> Therapy is important, but I do think that there's that caveat of really trying to find somebody who understands or at least who's willing to understand, because... I think that does do more harm than good when they don't, so it has to be the right fit.

Some participants commented on the need for *patient advocacy* (M3) to access supports, “I have to advocate for myself at all times,” though this comes with challenges: *“*it's so difficult to advocate for yourself when you're that burnt out.” The multiple barriers participants faced in their attempts to access support ultimately led to a *lack of trust in the healthcare system* (M4): “I felt hopeless and lost a lot of faith in the medical establishment that day.” Repeated misunderstandings led some participants to give up seeking help: “I didn’t seek help for a long time because, ah, what’s the point? Gonna be misunderstood again.” This theme is especially concerning as some participants expressed hesitancy about seeking help even in crisis: “After my experiences in the regular health system, I wonder if I would dare go that route in crisis.”

Finally, feeling disillusioned and unsupported by the healthcare system, most participants found *alternative avenues to support* (M5). Reliance on the *Autistic community* (M5a) was the most common avenue to education and support for autistic burnout, “I didn't know exactly what burnout was until I met other Autistic students,” and many realised they were experiencing autistic burnout through various social media platforms:

> I realized my experience was autistic burnout through TikTok and finding really fantastic creators who offered more detailed and nuanced explanations of how Autistic symptoms can present, especially in folks who are assigned female at birth and socialized as a woman.

Unfortunately, information from social media was frequently criticised: “as a therapist, as the social worker, that [TickTock information] was something that was so, within the community of like my colleagues, people viewed so negatively.” Other participants came up with creative ways of accessing support, such as *leveraging co-occurring conditions* (M5b): “I blame everything involving burnout as an issue of my “fibromyalgia” and it works to a point.”

Major Theme: Ineffective Treatment

Participants identified a variety of treatments that they felt were ineffective for autistic burnout. *Psychotherapies* (R1) were the most frequently cited as being unhelpful, with *Cognitive Behaviour Therapy (CBT)* (R1a) being the most referenced ineffective therapy: “I went through three more therapists over the years, all ones publicly funded or through my school, all CBT, and none who were neurodiversity affirming and never gave me anything that helped.” Other therapies included *Dialectical Behaviour Therapy* (R1b): ““…. Here is this DBT skill that may or may not work sometimes depending on the person” can be really detrimental and awful,” *Behavioural Activation* (R1c): “It felt like a lot more energy and work sustained,” *Post-Traumatic Stress Skills Group* (R1d): “I got referred to PTSD group therapy instead. Which proved to be useless and irrelevant,” and unspecified inpatient *skills group* (R1e): “A skills group isn't going to help as a lack of skills isn't the problem.” *Medication* (R2) such as anti-anxiety and anti-depressants were also perceived to be ineffective: “I was given SSRI's and other kinds of psychiatric medications that didn't help the burnout at all, of course.” *Neuronormative approaches* (R3) to therapy were also believed to be ineffective:

> They [therapists] were viewing all of my capabilities and like ways of being through neurotypical as the standard….I will never function like a neurotypical. They…have this very rigid idea of okay, this is how a person should be, and it’s like, they’re always trying to move their client into that.

Lastly, therapies branded as ineffective did not merely lack efficacy in the eyes of the participants but were perceived as being actively harmful. This sentiment is echoed in the recurring theme of *harm from ineffective therapies* (R4): “Other health professionals just tell me to exercise, take anti-depressants, and just go out more and enjoy life. Going out more puts me into a more severe burnout, it makes me worse;” “the idea of needing to push through and treating this abnormality... Reinforced a lot of those internalized messages that I was... Somehow deficient... And I came away feeling like there is something wrong with me;” “I…felt like an animal that has to be put down.” One participant articulated the harm caused by CBT specifically:

> when it is just CBT, I think can be damaging when if you have a belief, let's say or a thought, that “I just can't fit in this world... I just can't function the way other people have” well if the person doing the therapy isn't knowledgeable about autism, they might actually counter that as being a negative belief, like let's challenge this as black and white thinking, and then you get to have this almost gaslighting thing going on.

Major Theme: Effective Treatment

Fortunately, participants also revealed treatments deemed to be effective. For example, *psychotherapeutic approaches* (R5) typically applied to trauma such as *Acceptance Commitment Therapy (ACT)* (R5a): “Whenever you start to feel stressed out, see if you can hold a part of you that is stressed out a little bit more of a distance and... look at it and soothe it. It's sort of like that acceptance commitment therapy too;” *Eye-Movement Desensitisation and Reprocessing* (R5b) and *Internal Family Systems* (R5c): “really helped me in a focused sense of self compassion,” and *somatic therapies* (R5d), “for help regulating the nervous system, which goes hand in hand with burnout recovery.” *Interpersonal effectiveness* (R5d) was also perceived to be helpful, "because I felt like I could communicate to other people when my boundaries were being pushed." Multiple participants found *self-regulation techniques* (R6) (i.e. the act of controlling your thoughts, emotions, and behaviours) effective. For example, one participant described a "dinner party protocol" where they would "listen to loud music on heavy headphones while swinging in a hammock chair" before and after attending the party. Another participant found progressive muscle relaxation to be helpful. Relatedly, activities designed to increase vagal tone (such as exercising) was cited by a participant as beneficial, because "people with autism have low vagal tone and that can affect sensory issues."

On one hand, *non-psychological approaches* (R7) such as medication were found to be somewhat effective: "I was in and out of autistic burnout and depression for about a year then got on medication (Zoloft and Wellbutrin). It levelled me out in the burnout and the depression disappeared but there are significant side effects." On the other hand, another participant found occupational therapy helpful: "I'm only recently learning how to intentionally recover from stress because I've started working with an occupational therapist." Ultimately, the most frequently mentioned "treatment" was *basic supports* (R8). One participant explained, "if someone is experiencing autistic burnout... you almost want to do the opposite of like a hands-off approach," suggesting providers should be "more comfortable with, I guess, like blurring the boundary of like doing it for the client." In a rather unique approach, one participant's healthcare provider wrote,

> a prescription where you literally can't do anything for two months. Like that was her prescription was just like, you need to rest. And that was a little unconventional, but it was actually very helpful. Because it was getting... permission to just drop off the face of the earth for two months and I absolutely needed that.

Additionally, workplace accommodations were frequently mentioned as a useful *basic support*: "I have accommodations to work from home and flexible work hours," though many participants noted the difficulty in obtaining accommodations: "A long, complicated, and dehumanising ADA[2] accommodations process."

Recovery

Major Theme: Self-Management & Recovery

In the final major theme, participants described *self-management* strategies to manage and recover from autistic burnout on their own. In the subtheme of *time* (Y1), some participants expressed that recovering from autistic burnout is "like a cold where you can't speed it up," and they "need time to recuperate." Most participants underscored the necessity of *space* (Y2) for recovery, expressing sentiments such as "generally staying the heck away from people." The vast majority emphasised the need for *rest* (Y3): "I need quiet and rest to recover." The need for *planning & pacing* (Y4) activities was recurring theme: "I'm very intentional about what I plan, and I like planning in advance so I know what's coming and I can brace myself for it and pace it." Many participants described how having *self-knowledge* (Y5) is important to managing and recovering from autistic burnout: "I'm familiar to what I'm experiencing and know how to help myself as I learned a lot from last time." On the flip side, not having self-knowledge can be detrimental: "I didn't know what I was experiencing so could not deal appropriately with it." Associated with the five themes previously mentioned, the establishment of *boundaries* (Y6) concerning the responsibilities participants undertake emerged as an important factor in recovery, with one participant saying that they "allow myself to say "no" to things." About half of the participants engaged in *special interests* (Y7) as a means to recovery: "Allowing for extra time

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[2] ADA refers to the Americans with Disabilities Act, a law which provides protections for people with disabilities (*The Americans With Disabilities Act*, 2024)

for special interests," which also relates to *experiencing joy* (Y8): "Just go into my joys and focusing on that." Some participants found that at times, all they could do to manage was "seek distraction," "doing anything I could to avoid feeling," which is captured in the subtheme *distraction* (Y9).

Several participants discussed the need to spend time *unmasking*[3] (Y10), for instance, "having moments in the day where I'm not masking and can do stimming and other self-regulating activities." *Nutrition & movement* (Y11) was also recognised by some as beneficial: "Exercise and time in nature when tolerated." Furthermore, numerous participants required agency over their surroundings to manage and prevent autistic burnout, which was reflected in *environmental control* (Y12): "I'm more in control of my settings now and I can manipulate them to accommodate myself." Unsurprisingly, having a *supportive environment* (Y13) was frequently mentioned as supporting recovery: "Understanding from those around you goes a long way to making the process easier." However, *lack of support* (Y14) can make engaging in recovery strategies difficult: "it's just like having to pick which to worry about, like having money, or having space and time."

Additionally, some participants referenced *sensory considerations* (Y15) to manage symptoms such as heightened sensory sensitivity and minimise episodes of autistic burnout: "I put in some discreet ear plugs if the noise becomes too overwhelming. I wear a long sleeve shirt so that I have less skin for people to touch….I stick to safe foods." One participant explained how contact with *animals* (Y16) can be supportive: "I lay on the floor, and he [the participant's mum's dog] comes and he lays on my chest and I just sit there and I just like pet him and I didn't realise how much of that was so useful for me." Finally, multiple participants expressed concern

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[3] "Unmasking" is the term used to describe the act of allowing oneself to be their authentically Autistic selves, for example, engaging in stimming behaviours when they need to, and not forcing eye-contact.

over the possible permanence of lost function in *incomplete recovery* (Y17): “I kind of lost certain capacities and mental capacity, that I doubt will come back.”

Discussion

The current study sought to investigate the experience of autistic burnout, as well as the experience of accessing support for autistic burnout among Autistic adults. The findings of this study support the definition proposed by Raymaker et al. (2020) of autistic burnout, which describes it as a syndrome characterised by pervasive, long-term exhaustion, reduced functional capacity, and increased sensory sensitivity due to chronic life stress and masking, resulting in negative impacts on overall wellbeing. However, Higgins et al.’s (2021) preliminary defined criteria for autistic burnout offers a more complete description of the condition, as we found many participants also experienced interpersonal withdrawal, increased Autistic traits, and cognitive difficulties such as reduced executive function and dissociative states. Additionally, Mantzalas et al. (2022) suggested that autistic burnout is a chronic condition, a feature that was echoed by every participant in the current study. While Raymaker et al. (2020) specified a period of three months for the duration of autistic burnout, the present study, as well as Mantzalas et al. (2022), found that participants experienced both chronic and acute episodes of burnout. The similarities between our findings and that of previous researchers both validate and strengthen current definitions of autistic burnout. The growing body of evidence supporting autistic burnout as a chronic and debilitating condition highlights the importance of recognising autistic burnout as a diagnosable condition, especially given the high rate of reports of misdiagnosis.

It would be prudent to consider the impact of the male-centric diagnostic criteria for autism diagnoses, particularly given the gender bias present in the current study. The majority of the participants in the study identified as women or gender diverse, and many believed they had been misdiagnosed with borderline personality disorder, depression, and/or anxiety. Autism has been described as a male-typical neurotype since the publication of the first descriptions (Asperger, 2009; Kanner, 1943) and recent prevalence estimates put the ratio of male:female diagnoses between 4:1 (Werling & Geschwind, 2013) to 2:1 (Halladay et al., 2015). The Female Autism Profile (FAP) theory posits that the current diagnostic criteria and methods for assessing autism is unable to reliably detect autistic females, contributing to the comparatively low numbers of diagnosed autistic females (Dworzynski et al., n.d.; Russell et al., 2011). It has been suggested that the diagnostic bias is a result of the diagnostic criteria being based on pre-established conceptions of autistic traits developed from male populations (Rujeedawa & Zaman, 2022). This has significant implications; diagnostic bias results in systematic discrimination against autistic women and gender diverse people, as evidenced by the findings of this study.

Experiences Accessing Support

Thematic analysis revealed that the experience of Autistic adults seeking professional support for autistic burnout is predominantly negative, with participants facing multiple barriers to support. Firstly, lack of autism awareness was identified as the overarching theme across onset, accessing support, and recovery. Zerbo et al. (2015) has previously suggested that clinicians are able to recognise Autistic characteristics but lack the skills and tools necessary to provide care to Autistic individuals. In contrast, our findings suggest that clinicians lack awareness of the breadth and diversity of Autistic presentations and lack in-depth understanding of the unique challenges faced by Autistics, such as autistic burnout, substantiated by the frequent misdiagnoses and disbelief of autism diagnoses reported by the participants. This may be due in part to clinicians' stereotypical attitudes towards autism, which has previously been reported on (Brede et al., 2022). Clinicians have also commented on a lack of evidence, training and support for effectively working with Autistic adults (Ainsworth et al., 2020).

Secondly, every participant complained of a lack of support for Autistic adults; existing support services are often restricted to children or are financially inaccessible for underemployed Autistic adults. The vast majority of autism research and programming is focused on children, largely neglecting the needs of Autistic adults (Edelson et al., 2021). A report by Matthews (2016) found that a mere 1% of autism research funding is allocated towards researching autism in adulthood. Additionally, many of the participants in this study commented on being "too high functioning" to receive support. Research by Kenny et al. (2016) found that the term "high functioning" can underestimate the daily challenges faced by Autistic individuals. Bowker et al. (2011) revealed that people with Aspergers syndrome (now classified as autism spectrum disorder) are less likely to receive treatment compared to other subtypes, possibly due to perceptions of their coping abilities. This is particularly concerning, given the generally debilitating impacts to daily functioning during periods of autistic burnout, and the fact that multiple participants in the present study reported experiencing suicidal ideation and attempts. Previous research has already established that Autistic adults are at a higher risk for suicide than the general population (Cassidy et al., 2014, 2018; Hirvikoski et al., 2016). Suicide prevention programs should take into account the role of autistic burnout as a contributing factor to suicide, and clinicians should treat autistic burnout with the utmost concern.

Treatment & Recovery

The predominant portion of participants assigned female at birth in this study reported previous diagnoses of anxiety, depression, avoidant personality disorder, and/or borderline personality disorder prior to receiving their autism diagnosis. While this finding aligns with existing literature indicating a heightened propensity for Autistic females to be misdiagnosed (Fusar-Poli et al., 2022), it raises significant concerns in the context of providing treatment for autistic burnout. Higgins et al. have previously suggested that treatments for depression such as CBT and Behavioural Activation may be contraindicated for autistic burnout (2021). One of the most critical results of this research was the finding that participants viewed CBT and Behavioural Activation at best ineffective, and at worst actively harmful.

CBT is based on the premise that psychological problems are rooted in faulty ways of thinking, thus to improve psychological health, we must change the way we think by first identifying distortions in thinking and evaluating them against reality ("What Is Cognitive Behavioral Therapy?," 2017). However, for Autistic people experiencing burnout, their challenges in daily life extend beyond mere negative beliefs. Societal structures frequently fail to accommodate Autistic needs, thereby impeding Autistic individual's ability to thrive (Krieger et al., 2018). Consequently, attributing Autistic people's genuine struggles to "cognitive distortions" necessitating "reframing" puts clinicians at risk of invalidating the lived experience of the Autistic person and engendering perceptions gaslighting. Given the increasing numbers of those identified as Autistic (Matson & Kozlowski, 2011), the high rate of co-occurring conditions experienced by Autistic people (Lever & Geurts, 2016), and that the majority of therapists and psychiatrists use CBT in their practice (Brown, 2013; "How Many Psychiatrists Use CBT," 2006), it is of vital importance that front line mental health staff are aware of the risks of using CBT for Autistic populations and adapt their practice for this population.

Behavioural Activation (BA) is a specific CBT component frequently utilised to treat depression. Its underlying premise suggests that individuals experiencing depression engage in fewer activities, resulting in a reduced capacity to experience pleasure and interpersonal connection, consequently exacerbating depressive symptoms (Elfrey & Ziegelstein, 2009; Roshanaei-Moghaddam et al., 2009). BA aims to interrupt this cycle by increasing activity levels (Kanter et al., 2010). While this approach is effective for non-Autistic people experiencing depression (Ekers et al., 2014), the findings of the present study suggests that BA worsens autistic burnout symptoms as rest is required to recover. Involvement in activities beyond the capacity of an Autistic individual without sufficient rest has been associated with exacerbating and prolonging autistic burnout symptoms (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, Adikari, et al., 2022b; Raymaker et al., 2020).

The findings also revealed supports necessary for managing autistic burnout. Firstly, basic supports (such as practical supports, actions supporting rest, and workplace accommodations) were frequently cited as beneficial. Multiple participants expressed a need for practical assistance with daily tasks they could no longer manage due to symptoms of autistic burnout. Workplace accommodations were also highlighted as crucial, enabling Autistic individuals to remain employed while managing symptoms and preventing further burnout. Of note was the accommodation to work from home, which affords control of sensory environments and ensures a safe and private place to be able to unmask and engage in regulating stimming behaviours. While stimming behaviours are often vital for emotional and sensory regulation in Autistic people, they’re often stigmatized and viewed as unacceptable (Kapp et al., 2019). However, an important aspect of autistic burnout recovery involves dropping the “neurotypical mask” and engaging in self-regulating behaviours, such as stimming (Mantzalas, Richdale, Adikari, et al., 2022b). Additionally, many participants emphasised the need for schedule autonomy to facilitate pacing activities to ensure they’re getting enough rest between activities, which acts as both a recovery and preventative strategy for autistic burnout.

Several therapeutic strategies were identified that may be efficacious in treating autistic burnout symptoms. Some participants found ACT to be beneficial in reducing feelings of overwhelm while experiencing autistic burnout. ACT has previously shown promise in reducing psychological distress and improving adaptive functioning in Autistic individuals (Byrne & O'Mahony, 2020; Pahnke et al., 2014). Considering that autistic burnout entails reduced functional capacity and other distressing symptoms, ACT may be a promising treatment approach.

Interpersonal effectiveness approaches were also highlighted as beneficial, as it provides individuals with the skills to effectively communicate boundaries around their time and energy, preventing them from overburdening themselves which may trigger or worsen autistic burnout. Unfortunately, a systematic search of research databases focusing on interpersonal effectiveness skills training for Autistic people found scant results and was dominated by studies on social skills training. Social skills programs frequently posit the Autistic as a social "novice" with "deficient" social skills, while allistics (non-Autistics) are viewed as the "experts" with "superior" social skills. The goal of social skills programs is to teach the Autistic person to perform neurotypical social skills through mimicking "appropriate" communication and suppressing their authentic Autistic self (i.e. masking). However, masking Autistic traits has negative health consequences (Bargiela et al., 2016; Cage et al., 2018; Cassidy et al., 2018; Hull et al., 2017; Livingston et al., 2019; Mandy, 2019; Tierney et al., 2016), including autistic burnout (Arnold et al., 2023a; Higgins et al., 2021; Mantzalas, Richdale, & Dissanayake, 2022; Mantzalas, Richdale, Adikari, et al., 2022b; Phung et al., 2021; Raymaker et al., 2020). Social skills training has also been found to lack efficacy (Bellini et al., 2007). In contrast, the goal of the interpersonal effectiveness component of DBT is to get people to meet your needs and includes strategies for setting boundaries and making assertive requests while maintaining self-respect (Lenz et al., 2016), which may enable Autistic people to protect their energy and limit the need for masking. To the researcher's knowledge, only one study has been conducted on the efficacy of the interpersonal effectiveness DBT component in adults, though with promising results (Haney, 2018). More research is needed in this area to determine its efficacy and usefulness in mitigating autistic burnout.

Self-regulation techniques were also listed as helpful for coping with autistic burnout. Research indicates that Autistic people experience dysregulation at higher rates compared to the general population (Vasa et al., 2022). The present study suggests that episodes of severe dysregulation become more frequent during periods of autistic burnout, necessitating the need for effective self-regulation strategies. However, self-regulation strategies are not one-size-fits all. For example, some participants found breathing exercises to be ineffective, and certain mindfulness activities can be problematic for someone who experiences sensory sensitivities, as it can contribute to further overwhelm (Heidel, 2020). Some effective self-regulation strategies are neurotype-specific, such as stimming. Unfortunately, despite the clear benefits of stimming (Kapp et al., 2019) and the harm involved in supressing them (Charlton et al., 2021), researchers (and thus clinicians) continue to view stimming as a maladaptive emotional regulation strategy (Dell'Osso et al., 2023). Autistic people would likely benefit greatly in being supported to identify and access self-regulating activities which may reduce the frequency of burnout episodes and facilitate recovery.

Some participants highlighted the possible benefits of activities designed to increase vagal tone. The term "vagal tone" is a term referring to the activity of the vagus nerve: "high" vagal tone refers to increased vagal activity, which allows the body to recover quickly from stressful events. Several studies have indicated that Autistic people exhibit low vagal tone (Cheshire, 2012; Ming et al., 2016; Roberts et al., 2012) which may be linked to sensory processing difficulties (Schaaf et al., 2010). Autistic burnout, which can arise in part from sensory overload and lead to heightened sensory sensitivity, could therefore be mitigated through activities designed to increase vagal tone. Enhancing vagal tone may improve tolerance to sensory input, thereby potentially preventing Autistic burnout in some cases or reducing the distress associated with sensory exposure during episodes of Autistic burnout. However, a recent study found no association between autism and low vagal tone (Barbier et al., 2022). Consequently, activities aimed at increasing vagal tone to enhance tolerance to sensory stimuli may benefit only a small proportion of Autistic people who also experience autonomic dysfunction.

While DBT as a whole was considered to be ineffective by a number of participants, certain DBT skills such as interpersonal effectiveness and emotion regulation were considered valuable. A possible explanation for this contradiction is that DBT was developed to treat borderline personality disorder, a condition that many of the current participants were misdiagnosed with. Given this, the treating clinician may not have implemented the intervention with the understanding that the client is Autistic, therefore the treatment would not have been modified to suit specific Autistic needs, thus rendering the intervention only partially effective. However, a recent pilot study by Maddox et al. (2022) found that DBT-Skills Training shows promise as an effective treatment strategy for emotional dysregulation in Autistic adults, and Hartmann et al. (2012) has previously outlined several recommendations for adapting DBT for Autistic youth. In addition to those outlined by Hartmann et al., additional adaptations may include encouraging Autistic self-regulating behaviours (such as stimming and engaging in special interests), adapting the environment to better serve the Autistic individual in order to minimise the occurrence of emotional dysregulation, and ensuring that interpersonal effectiveness skills are taught in an Autistic-affirming manner.

Clinical Implications

The findings of this study have strong clinical implications. Firstly, all participants expressed a need for support, however due to the perceived lack of clinician knowledge and sparsity of services, most declared that they have not yet received effective professional support. As unmet support needs are a significant predictor of suicidality (Cassidy et al., 2018), this is of great concern. There needs to be greater support services for high masking Autistic people, such that these populations do not fall through the service gap. We also need higher standards of clinical competency around autism, specifically greater awareness of the diverse presentations of autism and the unique challenges faced by high-masking Autistics. Increasing education on autism may help prevent misdiagnosis and facilitate early detection, which will likely enable Autistic people to better understand their needs and implement strategies to better conserve their energy and mitigate the occurrence of autistic burnout. Furthermore, the available research suggests that clinicians lack knowledge on autistic burnout; it would be beneficial for future research to study healthcare professionals understanding of autistic burnout as this is currently absent from the literature.

Some of the services offered to Autistic people experiencing autistic burnout were not only ineffective, but also actively harmful. While this is likely due to lack of awareness of autistic burnout on both the clinician’s and individuals part, it highlights a need for greater care in offering treatments for Autistic people. Treatments such as CBT and BA should be implemented with the utmost caution given the risks. Given the symptom overlap of Autism with depression, and the propensity for clinicians to misdiagnose autistic burnout as depression, it may be beneficial to consider autistic burnout as a differential for depression, especially given the potential harms of mistreatment. Effective supports should focus on rest, regulation strategies, accommodations, and building interpersonal skills to effectively communicate boundaries. Moreover, involving the individual in treatment decisions is of vital importance. Similarly, treatments would likely be more effective if they are tailored to individual needs.

Strengths and Limitations

A major limitation of the study was the inability to confirm a diagnosis of autistic burnout among participants, as there are currently no validated definitions or screening tools for this condition. However, strong endorsement of core characteristics by participants indicates good content validity for the emerging definitions. The disproportionate number of female participants compared to males in the study led to a biased sample. Future research with larger and more balanced samples are needed to ascertain whether females are more susceptible to autistic burnout (and thus more attracted to studies on the topic), or if the observed gender bias is attributable to the higher participation rates of females in online autism research (Guo et al., 2017).

Given the limited resources of the study, we were unable to conduct clinical interviews with the participants, thus there is the potential that some participants were reporting on other conditions. Many of the participants had physical complaints such as gastrointestinal issues, migraines, widespread chronic pain, and more. Without a comprehensive clinical assessment, the present findings were subject to the influence of unidentified co-occurring conditions. Incorporating clinical assessments in future research will allow for the identification of co-occurring conditions that may confound results, thus enhancing the validity and reliability of future studies. Moreover, disentangling the impact of co-occurring conditions through assessment is particularly important given the high rates of co-occurring conditions within the Autistic population (Dovgan et al., 2023; Lai et al., 2020; Lever & Geurts, 2016; Owens et al., 2021).

Additionally, many of the participants were Caucasian and well educated, though unemployed. The homogeneity in this sample may limit the generalisability of the findings to the diverse Autistic population. Furthermore, all participants appeared to be verbal, as suggested by their participation in interviews or the information provided in their responses. This could further bias findings as it excludes non-verbal Autistic individuals who may have different experiences with autistic burnout and accessing support. Future research should prioritise a sample inclusive of non-verbal Autistics to explore the experiences of accessing treatment and support for autistic burnout in this group. This would ensure that the findings are inclusive and applicable to all individuals within the Autistic community.

An important limitation is that a few of the participants were therapists themselves, which may have led to a biased sample given the small sample size. This could mean that the results may not reflect the broader Autistic populations perspectives, as those responses were likely biased by their professional experiences. However, their dual perspectives as both professionals and Autistic individuals with experiences of autistic burnout may be a strength, as they were able to provide detailed and professional feedback on therapeutic approaches. While having therapists in the sample arguably limits the generalisability of the findings, it’s important to consider the possibility that research samples of autistic people, especially those who are high masking, are likely to contain Autistic people in the field of psychology. Anecdotal evidence suggests that some high masking Autistic people study psychology to better understand those around them (one of the key indicators of autism is differences in social communication and interaction) and to learn behaviours that help them blend in (Price, 2022). Thus, having several mental health care professionals in the sample arguably and reasonably reflects the Autistic population.

A validity concern of the study is the possibility that some of the difficulties experienced by the participants may have been related to common difficulties in clinical interventions. For example, while treatments for depression and borderline personality disorder have earned their place as gold standard treatments through repeated demonstrations of their efficacy in experimental research, they do not work for everyone. A limitation of the study was that clinician's knowledge of autism was not verified as the focus of the study was on Autistic perspectives. Given this, attributing treatment infectiveness, in whole or in part, to lack of clinician knowledge would be presumptuous. That being said, perceptions of clinician incompetence are of great concern, and these perceptions should not be quickly dismissed.

Conclusion

This research contributes to the increasing number of Autistic researchers studying autism with the aim of benefiting the Autistic community. This research, identified as a priority by the Autistic community, was designed, implemented, and interpreted by an Autistic researcher in collaboration with Autistic participants. Autistic burnout is a debilitating condition resulting from everyday stressors faced by Autistic people living in a world that was not made for them. Autistic burnout is frequently misdiagnosed as depression, anxiety, borderline personality disorder and other conditions. Based on the current research, mental health service providers often provide treatments that worsen autistic burnout, therefore there is a need for treatment approaches that effectively address the condition. This work adds to the growing body of evidence supporting autistic burnout as a syndrome deserving of a distinct diagnosis and provides the foundation for further research into effective treatments and supports for autistic burnout. More work is needed to increase clinician awareness of autistic burnout, and screening tools are necessary to facilitate accurate identification of the condition. Lastly, societal changes are necessary to address the neurotypical environments that contribute to autistic burnout.

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