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# Rethinking anxiety and depression for autistic adults through personal narratives: A mixed-method analysis of blog data

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## Abstract

**Background:** Autistic adults appear to be more vulnerable to anxiety and depression than their neurotypical peers. However, definitions of emotional well-being that are suitable for autistic adults are missing from this research, along with a missing complete understanding of what contributes to and alleviates negative emotions.

**Methods:** Autistic adults' experiences of emotions were systematically searched for within blog data from 26 autistic authors. The search strategy identified the context of emotions, without adhering to a priori definitions. Corpus-based and thematic analyses explored the most salient contributing factors and coping responses. Consultation with autistic adults directed the research.

**Results:** Negative emotions were most salient and were accompanied by qualifying descriptions of being intense and misrepresented by single-word labels. The impacts of negative emotions were pain and fatigue, disrupted self-care, housing and employment, and an accumulated toll on self-identity. Emotional regulation was achieved through monitoring physiological arousal, ownership of sensory and social stressors, investing in immersive activities, planning what to expect from daily life and rejecting deficit-based views of autism.

**Conclusions:** The findings offer some explanation for high estimates of anxiety and depression for autistic adults, by illustrating the unsuitability of neuronormative emotion concepts and assessment tools. There are significant implications for clinical practice, insisting on a formulation of difference rather than outdated practice that foregrounds deficit and disorder. We do not suggest that these views reflect the experiences of all autistic people. This study contributes a creative and participatory method to hear the viewpoint of autistic adults. A well-being resource is shared.

## KEYWORDS

anxiety, autism spectrum disorder, blogs, depression, mental health, qualitative research

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## 1 | INTRODUCTION

Within clinical practice and research that attempts to understand the emotional experiences of autistic people, there is a common, mistaken assumption that agreed definitions of anxiety and depression exist. Agreed definitions would need to be appropriately authored to represent autistic experiences, be fully and accurately described, and have value for the day-to-day well-being of autistic people (Fletcher-Watson et al., 2019).

### 1.1 | Overview of autism

Autism is a single label that represents a heterogeneity of neurological differences (Pellicano & den Houting, 2022). This important conceptualisation reflects the neurodiversity paradigm, which provides an understanding of autism with which the current research aligns. When described by autistic people, autism is a particular way of being and interacting with the world that is different from majority, neurotypical peers (Sinclair, 2010). Autism has been defined as a group of lifelong, heterogeneous, neurodevelopmental conditions, in which main differences are with social communication and repetitive behaviours, and often, the sensory experiences of the world (National Autistic Society [NAS], 2023; Späth & Jongasma, 2020). Also important is that autism presents in as many different ways as there are autistic people, as an autistic person interacts with their social world (Autistica, 2023). However, the most dominant way of understanding autism, especially within healthcare contexts, is through a neuropsychological lens and is aligned with the medical model of disability (American Psychiatric Association, 2013). This is an approach that enables diagnosis for many people. However, criticisms of this conceptualisation in the absence of autistic-authored definitions include the maintained viewpoint that autistic differences are always deficits, that autistic differences require intervention and that our collective aspiration within clinical practice is to change the experiences of autistic people to fit with societal conventions. Influential perspectives that support these criticisms can be read more fully in the works of Milton (2012) and Bottema-Beutel et al. (2021). Fortunately, new conceptualisations of autism are emerging within a neurodiversity paradigm, which recognise the experiences of being autistic and inhabiting a neurotypical world (Chapman, 2020). These are informing clinical practice (British Psychological Society [BPS], 2021a; National Institute for Health and Care Excellence [NICE], 2021).

### 1.2 | Overview of emotion

A helpful definition of emotion, across research and healthcare disciplines, is a transient, internal and subjective experience, with some marker of intensity or urgency, accompanied by thoughts and arousal in the body, which is broadly pleasant or unpleasant

#### Implications for practice and policy

- Anxiety and depression are summarising labels that likely give a premature and inaccurate understanding of emotional well-being for autistic adults. Existing assessment tools of anxiety and depression should be used cautiously.
- Emotional distress might be better understood as overwhelm or fatigue, which is an essential difference between autistic and neurotypical clients.
- We offer examples of how to formulate emotional distress for autistic clients, including the accumulated experiences of difference and marginalisation.
- Neutral language of characteristics, individual abilities or support needs are preferred to pathologising language of anxiety, depression, mood disorders and comorbidities.

(Mulligan & Scherer, 2012). Lists of basic emotions frequently include anger, fear, shame, sadness and joy. Broader conceptualisations consider the duration of emotion, the involvement of facial expressions and the actions motivated by emotion. For research and practice to be meaningful for autistic people, each of these variables needs to be considered from an autistic perspective. For example, the ability to notice signals in the body, or arousal, and associate these signals with emotion is known to vary widely for autistic people (Kinnaird et al., 2019), which suggests that subjective experiences of well-being and its communication must be considered when assessing mood. Preliminary research with autistic adults (Petty et al., 2022) and parents of autistic children (Bearss et al., 2016; Rodgers et al., 2016) shows confusion between emotional distress and sensory overwhelm, whereby sensory processing sensitivities provide missing understanding of what can contribute to emotional distress for autistic people, and can therefore direct meaningful ways to reduce emotional distress in ways that are different from increasing tolerance to negative emotions. Importantly, constructs of anxiety and depression are frequently applied in practice with autistic people without critical interrogation (Lever & Geurts, 2016). The implicit assumption that categorisations of mood disorders constructed for non-autistic populations benefit autistic people is detrimental for two main reasons. First, the potential for over-diagnosis of mental health disorders is being realised in the strikingly high prevalence estimates of anxiety and depression for autistic adults when compared with adults without autism diagnosis (Lever & Geurts, 2016; Wigham et al., 2017) and in personal narratives of diagnostic overshadowing and delayed autism assessment (Mandy, 2019). Second, in common psychotherapy practices, there is an unchallenged view that characteristics of autism are disordered (Petty, Hamilton, et al., 2023). A more nuanced understanding is that there are differences in emotional experiences for autistic people,

which need to be better understood within assessment, formulation and intervention, so as not to misrepresent autistic characteristics, anxiety or depression. Before accurate measures of anxiety and depression can be developed, a better understanding of how autistic individuals experience emotional well-being is required. Rather, a valid scale or metric of emotional distress for autistic people will be valuable, to offer an alternative to the existing scales of anxiety or depression. In this paper, we contribute to the argument that the common practice of assuming that a suitable working definition of emotional distress exists for autistic people must be rectified. We explore personal accounts of emotion by autistic adults to contribute to improved understanding.

### 1.3 | Autism and emotion

Research into the emotional well-being of autistic individuals typically foregrounds 'deficits' associated with autism, including difficulties recognising emotions in self and others (Uljarevic & Hamilton, 2013) or displaying fewer facial expressions and gestures (Trevisan et al., 2018). Differences in how somebody notices or expresses non-verbal communications, in and of themselves, do not represent well-being (Heasman & Gillespie, 2019). Within clinical practice, simplistic conclusions arise from the use of standardised assessment tools for anxiety and depression, as can be seen in research demonstrating high prevalence rates of anxiety and depression diagnoses for autistic people (Lever & Geurts, 2016). Common signs of depression, including reduced communication, social withdrawal or disrupted sleep, can have confounded explanations (Stewart et al., 2006). Low mood for autistic individuals might be indicated by different behaviours, including more intensity in focussed interests or need for sameness (Pezzimenti et al., 2019). Revised and developing assessment scales for children have benefited from removing some less-relevant assessment items and have added new items to assess sensory anxiety and tolerance of uncertainty (Bearss et al., 2016; Rodgers et al., 2016). These developments for children and young people need to be applied for use with adults. Additional caution with scales comes from the possible difficulty for autistic clients in inferring the precise meaning of questions, such as being sad 'all the time' (Cassidy et al., 2018). Camouflaging of differences can also cause difficulties with self-reports of mood in clinical contexts (Mandy, 2019; Trevisan et al., 2018).

It follows from this limited understanding of the emotional well-being of autistic people that therapeutic interventions to improve well-being are similarly constrained. Practitioners are asked to specialise in their practice and demonstrate their understanding of autism (BPS, 2021a; NICE, 2021). Currently, clinicians are guided to add on to their usual therapy practices, which understandably leads to inconsistency and varying suitability of approach (Ainsworth et al., 2020; Cooper et al., 2018; Spain & Happé, 2020; Walters et al., 2016; Young & Bramham, 2012). Some of these recommended adaptations to therapies include omitting

central components of the original therapies, or adding teaching of neurotypical skills, which limit their suitability. Psychological therapies are not yet designed with autistic experiences in mind; this is contributing to the reduced effectiveness of psychological therapies for autistic people (El Baou et al., 2023). Neurodiversity approaches ensure that we consider autistic characteristics as they are, with an understanding of the interaction between the person and their environment (Chapman, 2020). We align ourselves with the neurodiversity paradigm and designed this study accordingly. This study explores emotional experiences as authored by autistic adults.

### 1.4 | Blog data

A blog is a piece of autobiographical writing, akin to a diary entry, written by a single author on a social media platform (Jones & Alony, 2008). There are minimal requirements for blog writing, such that those choosing to write do not need invitation or screening can work from their chosen environment, can choose the topic, and language and can avoid reciprocal interactions, which are missing parameters from many research methods. Therefore, blog-based study can allow researchers to access populations that may otherwise be seldom heard (Wilson et al., 2015). This is important for this study. Blogs offer naturalistic qualitative data, outside of the influence of the researcher, and thus can provide a response to a research question without imposing a priori theory (Hookway, 2008). The absence of a social interaction, the blog author's control over the communication, and the unprompted opportunity for self-expression are qualities of blog data that have been described as reasons for blogging by autistic adults (Gillespie-Lynch et al., 2014). Beyond research, communicating online can empower belonging, community and advocacy for autistic people (Davidson, 2008). Blog research is demonstrating its value in amplifying the understanding on topics of autism research that have been missing personal perspectives, including diagnosis experiences of women (Harmens et al., 2022) and stimming behaviours (Kim & Bottema-Beutel, 2019).

The aims of this study were to explore emotional experiences as authored by autistic adults within a corpus of blog data, including contributing factors, felt experiences and responses to emotion. This offers a starting point for revising how emotional distress, including anxiety and depression, can be understood by autistic individuals. We align with the neurodiversity paradigm and designed this study to contribute a creative and participatory method to foreground the viewpoints of autistic adults.

## 2 | METHOD

Blog data were systematically searched to create a qualitative data set of emotional experiences authored by autistic adults. Analysis employed quantitative and qualitative methods, using corpus-based and codebook thematic analyses, respectively.

## 2.1 | Community involvement

Consultation with two autistic adults informed the study at three time points: to set the research question, locate reputable blogs and review the results. Study materials were shared with the consultation group 1 week before meetings to allow advance review. This involvement was an attempt to increase the relevance and reach of the research (Jivraj et al., 2014) and demonstrates some working within participatory research values, including respecting and taking seriously autistic voices (Fletcher-Watson et al., 2019). However, consultation is not a substitute for autistic-led research or autistic authorship, and we acknowledge this limitation.

## 2.2 | Data collection

A search protocol was generated following seven stages (Petticrew & Roberts, 2008): (1) defining the research question; (2) establishing inclusion criteria for blogs; (3) developing a strategy for locating blogs; (4) retrieving and screening blogs for inclusion; (5) quality appraisal of blogs; (6) systematic searching and extraction of descriptions of emotional experiences; and (7) analysing extracted data.

Blogs were identified via Google Search and the following blog host sites: Actually Autistic, Alltop, Bloggeries, Spoke and Bloglovin, using combinations of the following terms: blog (diary, personal stories and personal experience), forum (chat, chat room and discussion) and autism (autistic, ASD and Asperger's). Retrieved blogs, blog sites and autistic society pages were read for mention of additional blogs affiliated with autistic authors. Recommendations were sought from the consultation group. One hundred and two blogs were screened against the following criteria: written in English; by an adult aged 18 years or older; by an adult who self-identified as autistic; provided a description of personal experience on any topic; was available in the public domain without membership or password for access; was updated at least once per month; and was active for at least 1 year. Twenty-six blogs were included, featuring 1517 blog posts from 26 authors. Blogs were published between 2012 and 2022. The main topic of the blogs was to discuss general life experiences, such as experiences at school, work, travelling and daily events.

A total of 170 search terms were used to locate descriptions of emotional experiences in the included blogs and were informed by Medical Subject Headings, academic literature, thesaurus terms and close reading of the blog data set. Two members of the research team independently read a randomly selected sample (5%; 72,233 words) of the blog data set with content from all 26 blogs to identify discussions of emotion and update the search term list; 26 words were added. 'Meltdown' was included because blog authors used the term as shorthand for emotional distress. Behaviours associated with emotions, such as withdrawing, were not included unless accompanied by a description of emotion. The main author iteratively

updated the term list when extracting data for the study. No terms were added from the last 20% of blog data, giving some indication that all emotion words from this data set were included. The search term list is presented in Table S1.

All searched-for terms, along with surrounding text that fully expressed the emotional experience, were extracted and formed a qualitative data set. Five per cent of the study data was read by another member of the research group to check that the descriptions made sense out of context of the fuller blogs.

## 2.3 | Data analysis

### 2.3.1 | Part 1: Corpus-based analysis

A corpus is a large sample of written text, containing examples of naturally occurring or real-life language use (Baker, 2010). Corpus-based analysis is a well-recognised method of using computer software (WordSmith Tools version 8.0) to identify high-frequency descriptions or 'keywords' in text, and the patterns of language use around the keywords. In using this method, the blog data determined the analysis, without imposing a priori theory. The quantitative analysis reduces the influence of researcher assumptions (McEnery & Hardie, 2011). The study data set contained 410,114 words and was considered a good size for this analysis.

First, the study data were cleaned: spellings were standardised and converted into British English. Keyword analysis was then performed using a statistical comparison between the frequency of every word in the study data set with a reference data set, representing the general English language (Scott, 2021). The British National Corpus was used as a reference text, which consists of approximately 100 million words, including samples of written and verbal texts, fiction and non-fiction, published and non-published texts, collected from books, essays, journals, letters and conversations (Baker, 2010). Keywords are single words that occur more frequently in the study blog data when compared with the reference text, and when ordered by keyness, illustrate the salient or most representative language of the study data set. Keywords were manually joined if a root word appeared with different morphemes. For instance, 'feel', 'feeling' and 'felt' were combined. Non-descriptive grammar words (such as 'I' and 'it's') were deleted.

Second, analysis of collocation identified the most frequently used neighbouring words for each keyword, identifying words used within three-word positions on either side of the keyword. This illustrated the most salient descriptions of emotions beyond single words. This analysis assessed the strength of the relationship between the keywords and their neighbouring words, to determine whether the relationship was statistically significant and occurred more frequently than would be expected in general language use. The strength of relationship is illustrated by the Mutual Information score, which discounts high-frequency word pairings such as grammatical words occurring alongside keywords.

Finally, concordance analysis generated all lines of text containing each of the 20 top keywords, to situate the keywords back in their original context. The concordance lines formed a qualitative data set for thematic analysis.

### 2.3.2 | Part 2: Codebook thematic analysis

Thematic analysis was used to 'explore and develop an understanding of patterned meaning across the dataset' (Braun & Clarke, 2019, p. 848) with the aim of making sense of themes grounded in the data. Codebook thematic analysis offered a structured and transparent approach to theme development, in balance with the subjective interpretation of the data by the researchers and their values and knowledge (Braun & Clarke, 2019, 2022). We chose thematic analysis due to its flexibility of epistemological position (Braun & Clarke, 2006) and its compatibility with a critical realistic epistemological framework (Botha, 2021).

Thematic analysis was completed following six steps (Braun & Clarke, 2006). (1) The data were read repeatedly for familiarisation, with reference back to full blogs, with the researcher making note of patterns and impressions. The following questions were considered during familiarisation: 'How does this participant make sense of their experiences? What kind of world is revealed through their account?' (Braun & Clarke, 2012, p. 61). (2) Codes were assigned to all concepts that were relevant to emotional experiences. A codebook illustrated the codes, a corresponding working definition and example quotes. A 5% random sample of the data containing extracts from all blog authors was coded by a researcher independent from the research group with experience in conducting thematic analysis. Coding agreement is one way to inform a discussion about how well the blog authors are being represented by the analysis, hence, to what extent different researchers are inferring different meanings from the data. Agreement when coding this sample was 'substantial', illustrated by Cohen's kappa:  $\kappa = .799$ ,  $p < .001$ . Disagreements were used to reflect on the representation of the authors and to refine the codebook. (3) Codes were used as building blocks and were collated to develop themes from the blog data. Themes were 'clusters of meaning' that, together, represented the whole of the authors' discussions. Influence from researcher ideas and previous research was acknowledged explicitly in an attempt to create themes inductively from the data. (4) Themes were reviewed by the research group and the consultation group. (5) Themes were named to provide a representative and informative description of the data as a whole. (6) A final report was produced.

### 2.4 | Author positionality

Members of the research team have clinical and research experience of working with autistic clients. They are not diagnosed as autistic. Researcher influence was considered in the design and conduct

of the analysis: use of blog data, computational analysis, multiple raters, group discussion and consultation are illustrative examples. However, we acknowledge that this study was not designed or conducted by autistic researchers.

### 2.5 | Ethical considerations

The study was approved by York St John University School Research Ethics Committee. Issues of author consent and privacy were considered by the research team, in consultation with available guidance for conducting internet-mediated research (BPS, 2021b; Wilson et al., 2015).

## 3 | RESULTS

### 3.1 | Blog author demographics

The authors were mostly from the UK ( $n=12$ ), and also from the United States ( $n=8$ ) and the Netherlands ( $n=1$ ). Five authors did not disclose their location. Thirteen authors were aged 20–29 years, six were 30–39, five were 40–49, one was 50–59 and one was 60–69.

### 3.2 | Corpus-based analysis

Keywords are displayed in Table 1, showing the most salient words used by the autistic blog authors to express their emotions.

The most frequent descriptions were of negative emotions, including the following: anxiety, depression, upset and meltdown. This partly reflects the search strategy and its representation of both the blog data and wider academic literature on this topic. Positive emotions were not identified by this analysis. 'Sensory' was the second most salient keyword, indicating the close association between sensory experiences and negative emotion. The keyword analysis also suggests the importance of emotional well-being of 'neurotypical' comparison (and considering being 'able' and 'masking'), diagnosis, the impact of the COVID-19 pandemic and education settings. These were the priority topics of discussion alongside emotion for these blog authors.

Keywords with their most frequent neighbouring words are displayed in Table 2. These show markers of intensity that occurred with emotion descriptions. For example, 'anxiety', 'feel', 'depression' and 'upset' occurred alongside 'much', 'very', 'incredibly', 'severe' and 'really'. 'Anxiety' and 'depression' occurred frequently together, suggesting an overlapping experience. 'Social' descriptions and 'people' are suggested contexts for the autistic authors describing anxiety, depression and upset. 'Overload', 'processing' and 'sensitivity' give further detail of how sensory experiences relate to emotional well-being. 'Shutdown' appears as a synonym to 'meltdown'.



	Keyword	Frequency of use	RC frequency	Keyness log-likelihood	Keyness log-ratio
1	Anxiety	638	2587	3820.57	5.90
2	Sensory	331	622	2409.74	7.01
3	Feel	935	25,375	2402.04	3.15
4	Meltdown	198	42	1952.44	10.15
5	Neurotypical	113	0	1241.10	1062.17
6	Depression	232	2234	1028.39	4.65
7	Diagnosis	208	1718	980.14	4.87
8	Covid	83	0	911.61	1061.72
9	Mental	286	5732	887.75	3.59
10	Semester	95	37	887.10	9.28
11	Life	777	54,494	813.90	1.78
12	Understand	385	14,940	755.01	2.64
13	Overload	102	190	744.00	7.02
14	Incredibly	135	781	723.16	5.38
15	Brain	226	4580	697.03	3.58
16	Friends	353	14,577	656.16	2.55
17	Able	462	29,742	540.53	1.91
18	Burnout	50	14	482.04	9.75
19	Upset	154	3056	480.75	3.61
20	Mask	111	1192	469.96	4.49

Note: Log-likelihood values show the frequency of keywords. A log-ratio of 1 shows that a keyword was twice as frequent in the emotion data set when compared with the reference text. A log-ratio of 2 shows that a keyword was four times as frequent. RC frequency is the frequency that a keyword occurs in the reference corpus.

### 3.3 | Thematic analysis

Four themes were created: (1) expression of emotion; (2) causes of negative emotion; (3) impacts of negative emotions; and (4) coping strategies, as shown in Table 3.

1. Expression of emotion. Commonalities in how emotion was described by the blog authors were represented by the following subthemes:

#### 1.1. Emotion language.

Authors most frequently described negative emotions. Emotions were listed in close succession, suggesting the unsuitability of single labels, for example, 'I was feeling so lonely, isolated, angry' (Blog 2) and 'I felt inept, ashamed, unlovable, rejected, and I was always anxious' (Blog 5). Some authors described a limited range of labels for their emotions, such as, 'I had approximately four ways to describe my feelings: content, unpleasant, annoyed, or frustrated' (Blog 22). The majority of authors described difficulty expressing emotions, such as, 'I had a lot of feelings that I couldn't tangle out of my head... words are especially hard to come by these days' (Blog 11).

#### 1.2. Constancy and intensity of emotions.

Emotions were described as 'constant', 'permanent' and without reprieve; some authors felt 'on edge', 'near a breaking point' or

'burnout' (Blogs 6 and 7). 'In retrospect – I lived in a constant, and I mean CONSTANT, state of burnout. My nerves were always fried, my emotions always on edge, my ability to handle myself always dangerously near a breaking point' (Blog 7). Emotions were intense, too much and all-consuming. One blog author said, 'regulating emotions is extremely difficult' (Blog 11). Impacts described were constant negative emotionality becoming part of a person's identity and part of daily living: 'life is a constant series of moving from one anxious thing to the next' (Blog 13).

#### 1.3. Unexpected emotions.

Emotions were most frequently described as occurring without warning signs and were first noticed with meltdown or overload. Some authors said their emotions were noticed by other people. 'In struggles for everyday function, my emotions tend to get shoved to the background and not recognised or acknowledged until they build into 'overload'. Then it all comes out' (Blog 5).

#### 1.4. Emotions felt in the body.

How emotions were felt in the body was frequently discussed. Anxiety could be indicated by a fast pulse, weak hands and feet, pins and needles, stabbing and squeezing chest pain, stomach somersaults, stomach ache, pounding head and feeling 'dizzy, sick and disorientated' (Blog 24). Some of these

TABLE 1 Keywords in descriptions of emotional experiences ranked in order of keyword salience.

**TABLE 2** High-frequency collocates of keywords.

Keyword	Collocates
Anxiety	depression, social, people, experience, feel, much
Sensory	overload, issues, friendly, processing, input, sensitivity, autistic, anxiety
Feel	more, myself, really, better, much, guilty, bad, comfortable, anxious, very, sometimes, less, happy, sick, incredibly, uncomfortable
Meltdown	autistic, recovery, more, after, shutdowns
Neurotypical	people, autistic, world, person
Depression	anxiety, autistic, people, clinical, severe
Diagnosis	autism, self, official, officially, disorder
Covid	pandemic
Mental	health, illness, issues, other, people, autism, state, emotional, physical
Semester	fall, last, end, spring
Life	all, much, been, autistic, day, not, most, people, social, time, daily, own, college, part, real, normal
Understand	not, why, what, you, people, autism, never, more
Overload	sensory, anxiety, emotional
Incredibly	feel, difficult, frustrating, blessed, experience
Brain	like, body
Friends	family, who, people, make, all, close
Able	being, been, people, myself
Burnout	autistic, state
Upset	about, really, very, people
Mask	wearing

**TABLE 3** Overview of themes and subthemes from a thematic analysis of emotion descriptions by autistic blog authors.

Theme	Subthemes
(1) Expression of emotion	(1) Emotion language (2) Constancy and intensity of emotions (3) Unexpected emotions (4) Emotions felt in the body
(2) Causes of negative emotion	(1) Uncertainty, unfamiliarity and change (2) Interpersonal communication demands (3) Sensory processing demands (4) Disabling environments
(3) Impacts of negative emotions	(1) Negative judgement from self and others (2) Impacts on living
(4) Coping strategies	(1) Sensory ownership (2) Movement and rhythm (3) Self-care activities (4) Help from others (5) Professional support (6) Minimising stressors (7) Self-understanding

physical sensations were likened to a storm by one author. Monitoring physical sensations was used to improve emotion awareness.

- Contributing contexts to negative emotions are described under the following subthemes:

2.1. Uncertainty, unfamiliarity and change.

These were discussed by all autistic authors as contributors to negative emotions, such as anxiety or terror. Not knowing 'what the future holds' (Blog 2) and the unknown in abstract terms were discussed. More specifically, new situations caused



anxiety if the person did not know 'how to behave or what to expect' (Blog 1). Change to routine also caused upset. Most commonly, not being able to plan flexibly for how to cope in new or unknown situations caused negative emotions. Being without a routine or plan caused upset. Anticipating change ahead of time caused fear. Consistency in what to expect from daily life was an important contributor to emotional well-being.

#### 2.2. Interpersonal communication demands.

Misunderstandings in communication were described as placing demands on the autistic authors. Some authors said they felt this demand when finding words, keeping a fast pace of conversation, when expected to maintain eye contact or contribute to small talk, as well as responding to behaviours of others: 'Our difficulty in understanding other people can also make us feel anxious. How am I meant to not feel anxious when I have no idea what this person is thinking or what their facial expression means? When their behaviour seems so unpredictable and illogical to me?' (Blog 1). The consequences of anticipated miscommunication included worrying ahead of time. Miscommunication contributed to freezing, accumulating frustration and feeling drained of energy.

#### 2.3. Sensory processing demands.

Sound, light and visual details, and touch sensations were said to contribute negatively to emotional well-being, including 'people talking' and 'music blasting' (Blog 15), high temperatures and bright sunlight, leading to overload and meltdown. Particularly demanding environments included airports, pubs, restaurants and education settings.

#### 2.4. Disabling environments.

School, college and workplaces, and accompanying expectations to perform in line with neurotypical peers, could cause some authors to feel 'drained and exhausted' (Blog 10). Difficulty understanding unspoken rules and expectations in these environments caused confusion and fear. These environments could be disabling by failing to implement adaptations for neurodivergence, such as classrooms causing sensory overload.

### 3. The following subthemes describe the impacts of experiencing negative emotion:

#### 3.1. Negative judgement from self and others.

Authors said they feared showing emotion to others, notably when emotions were intense and could be judged negatively, feeling 'chastised' (Blog 5), experiencing 'impatience or dismissal or anger' (Blog 7). Some felt disapproved of, or naughty. Some authors said they felt frustrated with themselves for experiencing strong emotions. Secondary emotions could include embarrassment and shame.

#### 3.2. Impacts on living.

Negative emotions could have immediate painful and fatiguing impacts. Prolonged negative emotion could cause longer term negative consequences in domains of self-care (such as getting out of bed and making food), maintaining meaningful routines, difficulties sustaining accommodation and keeping employment. One author said that life became 'chaos' when

their mental health deteriorated: '...as my mental health deteriorated, so did my routine. My life was chaos' (Blog 23).

### 4. Coping strategies. Autistic bloggers discussed how they reduced emotion intensity in the following ways:

#### 4.1. Sensory ownership.

Sensory ownership was achieved by reducing noise. One specific strategy included wearing noise-cancelling headphones. Yoga and walking helped one author to move away from noise. Emotional well-being could be enhanced by listening to music as an 'escape' (Blog 12) and by seeking touch, such as 'textured sensory bags', or by rubbing their arms or embracing themselves (Blog 18). Other authors sought particular preferred flavours or bland foods.

#### 4.2. Movement and rhythm.

Repetitive movement was frequently described as both reducing intense emotions and contributing to calm feelings, with one author saying they moved 'for as long as necessary to feel calm' (Blog 18). Movements included rocking, rocking from heel to tiptoe, walking, fidgeting and flapping.

#### 4.3. Self-care activities.

Self-care activities were described as helping to regulate emotions, and included exercise, cooking, video-gaming, reading, walking, colouring and listening to music. Activities were chosen to block out distressing thoughts and sensory stimuli by moving away from stressful contexts and by allowing 'immersion' (Blog 19) in a chosen task. Some authors planned meaningful distracting activities for when they returned home from their day. Most authors listed more than one strategy for the same situation, so they had options to choose from.

#### 4.4. Help from others.

Some authors said they found it difficult to think about methods of coping when they felt distressed. In these situations, they described needing help from others, such as from chosen family members and friends, to help reduce negative emotions. Help could include being supported with relaxing breathing, being helped to find space or find a distracting activity.

4.5. Professional support. The majority of the bloggers described receiving a variety of helpful interventions from professionals to support their mental well-being. The two main forms of professional help included medication to minimise anxiety and talking therapy to make sense of emotions.

#### 4.6. Minimising stressors.

Some authors said they improved their emotional well-being over time with practical planning, including using a schedule or diary to plan ahead and manage anxiety. In part, this helped to organise responsibilities, such as paying bills.

#### 4.7. Self-understanding.

Many authors said that their emotional well-being improved with increased understanding of themselves. This was mostly discussed alongside receiving a diagnosis of autism or learning more about autism, such as through reading the experiences of autistic peers. 'I think about how much life has improved for me with my new understanding of my own

autism and how much diagnosis meant to the difference in my life from “survive” to “thrive” (Blog 5). Things that had been different for them throughout their life when compared with their neurotypical peers made more sense. Some said that receiving a diagnosis of autism made them feel connected to others.

## 4 | DISCUSSION

This study updates the current understanding of the mental health of autistic adults with an overview of the most salient factors contributing to emotional well-being and a characterisation of emotional distress based on first-hand accounts. The study was designed to foreground autistic voices and to minimise a priori assumptions of mood disorders with an analysis of naturalistic blog data written on the topic of everyday experiences. This is a new and essential point of reference for psychological practitioners. Findings offer the following updates to our understanding of anxiety and depression for autistic clients.

First, anxiety and depression are summarising labels that likely give a premature and inaccurate understanding of emotional well-being for autistic adults. The self-authored descriptions in this study suggested the prominence of anxiety and depression for autistic adults, as illustrated by corpus-based analysis, which is consistent with high prevalence estimates of mood disorders for autistic people (Lever & Geurts, 2016). However, findings illustrated their over-simplicity. Autistic authors demonstrated that single words did not convey the extent of their emotional experiences. The fuller context of emotion descriptions showed that these autistic adults drew upon widely variable personal language, they overlapped emotion labels, they often missed milder or accumulating emotions and they experienced overload, burnout or meltdown. Emotional distress was not easily disentangled from a more valuable concept of fatigue. Fatigue worsened with sensory demands and efforts made to behave like neurotypical peers, illustrating essential differences between autistic and neurotypical clients. In agreement with the existing literature (Cassidy et al., 2018; Wigham et al., 2017), the findings of this study oppose the use of existing assessment tools for understanding the emotional well-being of autistic clients. Assessment scales mis-tell the story of what anxiety and depression are, and can negatively label autistic characteristics. More helpfully, differences in emotional experience offer a starting point from which emotion can be explained, for autistic people personally, with their friends, family and clinicians. The body's physiological expression of emotion as a useful signal for emotional regulation is a valuable research finding. A metre or scale of overwhelm or fatigue would likely offer a better metric of emotional distress than standardised tools for assessing anxiety or depression. The wider significance of this recommendation is the potential reduction in misdiagnosis, diagnostic overshadowing, over-medicating and personal confusion associated with mental health labelling of autistic characteristics.

Second, we offer guidance for formulating psychological distress (BPS, 2021a; NAS, 2022; NICE, 2021). The following conditions are likely to contribute to negative emotions for autistic adults in the immediate term and can inform a psychological assessment and intervention plan: difficulty anticipating what unknown future events will be like and being without a plan, deviation from familiarity (including routine, rules or a familiar environment), unchecked expectations to engage with neurotypical communication preferences and sensory demands in environments. A repertoire of coping strategies designed with understanding of autistic neurological differences intuitively then include the following: reprieve from social and sensory demands, search for familiar and preferred environments, comfort from repetitive behaviours, immersion in tasks, calming and coping through sensory ownership and help from selected others. These are consistent findings from across the lifespan (Bearss et al., 2016; Petty et al., 2022; Robertson et al., 2018; Rodgers et al., 2016; Spain & Happé, 2020). In the longer term, clinicians must consider the accumulated experiences of difference for an autistic client, of inhabiting disabling environments, and accruing negative judgement from others and self, and the consequential impact on self-esteem. Autistic individuals might describe hopelessness, pessimism or self-deprecation more than what is traditionally understood as low mood (Bearss et al., 2016; Gotham et al., 2015; Uljarević et al., 2018). Autistic adults in this study described being judged as naughty, shamed and dismissed when they expressed negative emotions, which was often set against a backdrop of neurotypical comparison and expectations. Differing paradigms of understanding were apparent in the authors' descriptions of their well-being. A medical model of noticing deficits, such as with keeping pace in conversations or making eye contact as part of social communication expectations, could cause worrying, freezing and frustration; this was in contrast to stronger self-advocacy and improved well-being described when authors explicitly discussed their perceived expectations to behave in neurotypical ways, such as at school and in workplaces, aligned with a neurodiversity affirmative perspective (Pellicano & den Houting, 2022). We understand that diagnostic labels and premature misunderstandings can become part of a person's identity and come to be used to explain times of feeling different (Harmens et al., 2022; Mandy, 2019). Belonging is an influential contributing factor to autistic well-being and often occurs alongside learning about autism from autistic peers, which can be difficult to find amongst commonly reported experiences of bullying and exclusion (Milton & Sims, 2016; Petty, Allen, et al., 2023). Education and workplace settings seem to be particularly influential in highlighting negative differences for autistic students and employees (Mesa & Hamilton, 2022), including the toll of sensory demands and ambiguous social behaviours (All Party Parliamentary Group on Autism, 2017; Lindsay et al., 2021). Education settings and workplaces simultaneously offer the potential to welcome and celebrate neurodivergence (Hamilton & Petty, 2023).

Third, it follows that therapeutic interventions must be designed for autistic clients, with understanding of autism and the

contexts in which autistic people live. Cognitive behavioural interventions that understand emotional distress as being caused by how a person interprets a scenario, thus activating negative beliefs held about the self in the world (Beck, 2005), are likely to be inappropriate if the environment is inherently distressing. It is valuable to recognise how characteristics of neurodivergence might precede or interact with negative life events (Griffiths et al., 2019; Young & Bramham, 2012); however, psychological formulation must not only see deficits (Mandy, 2019). The task for improved emotional well-being for autistic clients is to reassert an understanding of self with different perceptual or thinking abilities in a world that is neurotypical by majority. This should be an essential standard underpinning the well-being of autistic people. A priority therapeutic task is to build personal agency over what contributes to emotional well-being, including modifying the habitat. In this study, autistic adults shared their learned resources that came with self-understanding. Petty, Hamilton, et al. (2023) offer a freely available emotion worksheet to promote emotional insight and well-being, which was designed without the assumption of emotional experience being disordered.

Finally, clinicians are in a position to make simple modifications to their practice to influence societal change about how mental health is understood (Bottema-Beutel et al., 2021). We can achieve this by avoiding the language of pathology (such as symptoms, comorbidities and mood disorders). For example, the findings of this study demonstrated how autistic adults took ownership over interpersonal communication differences, sensory habitats and ways to achieve familiarity and rhythm, but we choose not to adopt the language of diagnostic symptoms when discussing these (American Psychiatric Association, 2013). We favour neutral descriptive language (such as characteristics, individual abilities or support needs; see Bradshaw et al., 2021, for a discussion of language choices). This can be difficult, particularly when 'anxiety' is often better understood in practice than sensory exhaustion or social fatigue. We, therefore, need incremental changes in the methods used by clinicians to assess and understand well-being of autistic clients, to prevent misdiagnosis of mental health disorders.

These recommendations align with core principles for working in a social justice-informed way with autistic clients (Petty, Hamilton, et al., 2023). A temptation to offer serial, individual-level interventions, such as for social skills or depression, or anxiety, should be a red flag to psychological practitioners. This study demonstrates how autistic neurological differences might underpin some ways in which emotional well-being can be better understood. A larger piece of societal work is to share this responsibility. An anticipated refocus will be on interventions to improve the physical and social environment, and promote belonging. Both autistic and neurotypical individuals might learn vital skills from one another (Mitchell et al., 2021). Future research in this direction would respond to multiple demands from the autistic community for research to have a direct benefit to autistic individuals' day-to-day lives and build upon the support currently provided by services (Fletcher-Watson et al., 2019).

## 4.1 | Strengths and limitations

Design details of this study provide an example for researchers who want to adopt creative methods (Brooks et al., 2020). In using blog data, we emphasised finding data, rather than producing it, in order to understand autistic differences. We addressed outstanding priority topics for research (Nicolaidis et al., 2019). We sought to conduct meaningful research through consultation, unobtrusive sampling of naturalistic data and team working to reduce the influence of pre-existing beliefs about autism. Blog-based research was a way to extend the reach of autistic advocates who are writing to educate others (Gillespie-Lynch et al., 2014; Rains & Keating, 2011). Online sampling meant that we heard perspectives from across the UK, the United States and the Netherlands. In these ways, this study demonstrates some examples of working within participatory research values, including respecting and taking seriously autistic voices and authentically listening to the expertise of the autistic authors (Fletcher-Watson et al., 2019). We implemented participatory guidance by being transparent about the role of consulting; we offered choice over when, how and on what aspects of the research to contribute. However, we would like to acknowledge some limitations. Autistic individuals should set the research question and determine how the research gets done through partnering or leading, which was not achieved in this study. Autistic people were consulted at three time points, to review the research questions and sources of data collection, early results and the interpretation of findings. Blogging will foreground the views of those who are able to navigate social media, write in the English language and speak with insight into personal experiences. Whilst replicating emerging understandings from across a growing body of lifespan research, the study findings will not represent all autistic people, of all abilities and communication styles. The research group do not identify as autistic and cannot bridge the gap of potential misunderstandings when sharing different subjectivities from the research participants (Heasman & Gillespie, 2019; Milton, 2012). Additionally, using extant data meant there was no opportunity to improve shared understanding. This study is not a substitute for autistic-led research or autistic authorship. Finally, we continue to reflect on the challenges of analysing data with mixed quantitative and qualitative approaches (Onwuegbuzie & Leech, 2005), though we believe the benefits of both have come together in this study to fairly represent the perspectives of the blog authors, as was our intention.

We believe the findings will be valuable for individuals who identify as autistic and who are formally diagnosed, given the replication of previous findings (Petty et al., 2022), but caution that they offer guidance only.

## 5 | CONCLUSIONS

The findings offer some explanation for the high estimates of anxiety and depression for autistic adults by illustrating the

unsuitability of neuronormative concepts and assessment tools, which oversimplify emotional well-being. A metre or scale of overwhelm or fatigue could offer a better metric of emotional distress. We consider implications for clinical practice, insisting on a formulation of difference rather than deficit and disorder, and give examples of important considerations for psychological practitioners. We offer a freely available emotion worksheet to promote emotional insight and well-being (Petty, 2023). This study contributes a creative method to foreground the views of autistic adults, though these views will not represent the experiences of all autistic people.

### CONFLICT OF INTEREST STATEMENT

The authors have no conflicts to declare.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon request from the corresponding author.

### PATIENT CONSENT STATEMENT

The study was approved by York St John University Research Ethics Committee, RECCOUN00021. Issues of blog author consent and privacy were considered in consultation with available guidance for conducting internet-mediated research (BPS, 2021b; Wilson et al., 2015). Blog authors were not approached for consent.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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