## Title

Revising our understanding of emotional distress for autistic adults; call for research


## Abstract

Autistic adults are more likely to receive diagnoses of anxiety and depression than their non-autistic peers. This means that clinicians need an improved understanding of what emotional distress is for autistic people, the causes and appropriate therapeutic interventions. A small sample study adopted a survey and interview design with four autistic adults with cooccurring mood disorders. Emotions were unexpected and overwhelming, were caused by fearing the unknown, loss of control, sensory demands, injustices and accumulation of everyday stressors. Autistic patients coped with emotions by withdrawing and with practical help to remove what was causing the distress and provide reassurance, though this was to be offered only when requested and only from specified people in order to reduce further unwanted demand. These preliminary findings suggest the direction of change in our understanding of mood disorders in autistic populations. We discuss this challenging area of study with considerations for practitioners and researchers.



## Keywords

Autism spectrum disorders; therapy; emotions; mental health

Autistic adults are more likely to receive diagnoses of anxiety and depression than their non-autistic peers, with as many as 57% of autistic adults receiving mood disorder diagnoses compared with 18% of their peers (Lever & Geurts, 2016). This presents two questions. First, how do characteristics of autism contribute to vulnerabilities for mental ill-health (Hedley et al., 2018)? Second, perhaps more accurately, how can our default definitions of mood disorders be revised with an autistic perspective (Bearss et al., 2016; Uljarević et al., 2018; Wigham et al., 2015)? Mood disorders are experienced and expressed differently by autistic people (Bearss et al., 2016; Uljarević et al., 2018; Wigham et al., 2015). Some descriptions of mood overlap with autism, thus contributing to false-positives; and, conversely, some descriptions of distress are missing, reducing the sensitivity of assessment tools that are normed with non-autistic samples. Differences for clinicians to be aware of include how autistic patients recognise and regulate emotions, how they process sensory information and reduce uncertainty (Maisel et al., 2016; Wigham et al., 2015). Where mood disorders are being misunderstood, there are multi-fold implications of delayed and inappropriate treatments and personal confusion (Maddox et al., 2020).

Due to the characteristics of autism, adjustments often need to be made to care, including ensuring that services are accessible and that therapy interventions are appropriately tailored (Cooper et al., 2018; National Institute for Health and Care Excellence, NICE, 2016; Petty et al., 2021; Spain & Happé, 2020). This comment highlights the increasing likelihood that clinicians working across mental health and neurodiversity services will need a relevant understanding of how emotional distress is experienced by autistic individuals.

**Small Sample Study**

Adults who received a diagnosis of Autism Spectrum Disorder without intellectual impairment from a specialist clinic funded by the NHS in the UK were invited to participate

in an online survey. An autistic expert-by-experience and a clinical psychologist co-created the survey questions. Thirty-five patients were approached and four completed the survey. The small participant sample is discussed. Two patients indicated that they were male, two indicated that they were female. Patients had cooccurring mental health diagnoses of depression and anxiety and had attended psychological therapy or received medication for mood. This sample represents real-world clinic presentations. Patients answered questions about their experiences of anxiety and depression, including contributing factors and ways of coping. An alexithymia scale was included; the mean score indicated alexithymia, which is consistent with the higher prevalence of emotion processing difficulties in autistic people when compared with neuroconvergent or neurotypical communities (Kinnaird et al., 2019). One participant took part in an exploratory semi-structured video interview to expand their survey responses. Thematic analysis (Braun & Clarke, 2006) revealed four themes, as shown in Table 1.

**Revised Descriptions of Emotions**

Anxiety and depression were described as: feeling scared, dreading, trapped, overwhelmed or helpless. Further to anxiety and depression seeming overbearing, emotions could feel ‘clipped’ or limited in range, and could escalate from limited awareness to emotion overflow. Patients described slow processing of how they felt and why. These descriptions resonate with alexithymic definitions (Bird & Cook, 2013). Emotions were little-considered until an unexpected problem could not be resolved. Thus, emotional distress was not anticipated, was felt strongly and was difficult to tolerate. Sensory experiences, including sensitivity to smells and sounds, sensory ‘pressure’ or sensory ‘overload’ (Wigham et al., 2015) contributed to anxiety and were worsened by anxiety.

**Unique Causes of Emotional Distress**

Fearing the unknown (Maisel et al., 2016), loss of control and over-stimulation (Cooper et al., 2018; Maddox et al., 2020) contributed to depressed mood and anxiety, reflecting existing understandings of autism and mental health. Additionally, injustices or broken promises were a cause of distress. Different causes of anxiety have been similarly reported by family members of autistic children (Bearss et al., 2016). One patient explained that emotional distress was partly caused by having a brain that 'grinds to a halt' with everyday stressors. This reflects executive and sensory processing difficulties (Cooper et al., 2018; Maddox et al., 2020).

**Personal Coping**

Ways of coping with depressed mood and anxiety were to withdraw and hide away. Impulsive spending, such as to invest in a specific interest, was a theme of coping. At interview, when asked about similarities or differences with the emotions of other people, one patient said they don't relate to the emotions of other people (Cooper et al., 2018), suggesting limited learning of tolerance and coping. Autistic individuals have previously described reduced quality of life relating to social relationships and loneliness (Hedley et al., 2018).

**Helpful Responses from Others**

Requests for support from other people were practical and solution-finding, which participants said they would seek when they needed. First, a priority was to remove causes of distress, such as leaving an upsetting context or having time-out alone. Second, a helpful response was to guide relaxed breathing or for somebody to manage risks of ongoing harm. Third, patients requested reassurance, such that distress will pass. Notably, helping responses were from specified and trusted people only, such as a family member, and were from one

person at a time. This was in the context of autistic patients expecting to be misunderstood and wanting to minimise social and communication expectations.

**Table 1**

*Themes within anxiety and depression descriptions given by autistic individuals (n=4)*

| Themes and Subthemes | Exemplary Quotes |
|---|---|
| **Revised Descriptions of Emotions** | |
| **Emotion intensity:** emotions are felt strongly and are difficult to tolerate | It feels like I'm trapped and there's no escape. It also feels scary, P1; it's just a big mess trapped in your mind and it hurts… an overflow of emotions, P3 |
| **Limited emotional range** | it feels like my emotional dynamic range has been clipped as opposed to compressed, P2 |
| **Limited emotion awareness:** emotions escalate from limited awareness to emotion overflow | I feel myself losing control… sometimes I just feel that way without a reason, P1; I can't explain myself, P3 |
| **Slow processing of emotions:** slow processing of what is being felt and why | my mental processes hit boundaries that are not normally there… my brain grinds to a halt, P2 |
| **Interaction with sensory sensitivities** | I can hear things I normally ignore, P2; sensory overload… cooking smells and other sensory pressures, P4 |
| **Unique Causes of Emotional Distress** | |
| fearing the unknown | unexpected events, upcoming events, upcoming appointments, uncertainty, P4 |
| being without control | an irreversible situation that greatly impacts me and over which I do not have control, P2; things that make managing my depression worse: stress, time pressures… the news… bad weather… social media… conflicts… feeling overwhelmed… anything that I'm not in control of, P4 |
| injustices or broken promises | injustice as a consequence of irresponsible human behaviour, P2; promises being broken, P3 |
| **Personal Coping** | |
| withdrawal | I try to avoid personal contact as much as possible, P2; go home, withdraw… eliminate uncertainty, P4 |

| | |
|---|---|
| impulsive spending | I buy things online, P1; overspend money, P2 |
| **Helpful Responses from Others** | |
| remove causes of distress | try to offer solutions to my problems, P2; a time out away from whatever… a small amount of positive with not negative does make me kinda happy, P3 |
| guide relaxed breathing and manage risks of ongoing harm | be aware that I might be at risk [relating to self harm and dissociation]… help manage my breathing, P4 |
| give reassurance | just tell me I'm going to be okay, P1; overcome my initial rejection and come say nice things to me, P2; remind me that the anxiety will pass eventually, P4 |
| from specified and trusted people only | I do want familiar people's positive attention but at the same time I think I'd want it in a certain way because social things make me uncomfortable, P3; leave me alone, but be there when I need them, P4 |

**Comment**

This comment is informed by a small pilot study and suggests the likely direction of change in our understanding of mood disorders in autistic populations. The means of acquiring a personal autistic perspective of mental health, as reflected in this small sample study, is challenging for three reasons. Describing emotion requires insight (Bird & Cook, 2013); it requires an interpersonal conversation (Cooper et al., 2018; Petty et al., 2021); it has the potential to cause distress, raising ethical considerations for research design. These were encountered in this study. The alexithymia scale showed impaired ability to identify, understand and describe emotions in all patients. On completion of the survey, patients indicated 'seven-out-of-ten' difficulty answering the questions. Furthermore, across four questions asking for emotion descriptions, causes and coping, answers were blurred, for example, behaviours were described when asked 'how does it feel?' In the case interview, these challenges were described. Collectively, these also illustrate difficulties observed in clinical practice when attempting to understand mental health for autistic adults (Cooper et al., 2018; Petty et al., 2021). These need further consideration to allow for meaningful, inclusive research (Fletcher-Watson et al., 2019).

These preliminary insights from autistic patients are consistent with specialist knowledge held by clinicians who attempt to adapt psychological therapies for their autistic clients, which they do by giving emphasis to emotion psychoeducation, reducing sensory and environmental exhaustion, reducing social expectations and increasing certainty around what to expect (Cooper et al., 2018; Petty et al., 2021). They also offer a starting point for the formulation of emotions within therapy. Whilst holding in mind a helpful curiosity of the evolving understanding of autism (Hobson & Petty, 2021), these results give us necessary caution when presuming that default definitions of anxiety and depression are specific, sensitive and valid for autistic individuals. This is a call for further research into how to tailor

mental healthcare for autistic patients (NICE, 2016). Future research should adopt a neurodiversity framework (Pellicano & den Houting, 2021), without assuming deficit, making comparisons with neurotypical patients, or simply using "add-ons" to traditional therapeutic approaches.

## Data Availability

The datasets generated during the study are available from the corresponding author on reasonable request.

## Compliance with Ethical Standards

The authors have no relevant financial or non-financial interests to disclose.

**References**

Bearss, K., Taylor, C. A., Aman, M. G., Whittemore, R., Lecavalier, L., Miller, J., Pritchett, J., Green, B., & Scahill, L. (2016). Using qualitative methods to guide scale development for anxiety in youth with autism spectrum disorder. *Autism, 20*(6), 663–672. https://doi.org/10.1177/1362361315601012.

Bird, G., & Cook, R. (2013). Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism. *Translational Psychiatry, 3*(7), e285.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cooper, K., Loades, M. E., & Russell, A. (2018). Adapting psychological therapies for autism. *Research in Autism Spectrum Disorders, 45*, 43–50. https://doi.org/10.1016/j.rasd.2017.11.002.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: shaping autism research through meaningful participation. *Autism, 23*(4), 943-953. https://doi.org/10.1177/1362361318786721

Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2018). Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders, 46*, 1–7. https://doi.org/10.1016/j.rasd.2017.11.003.

Hobson, H., Petty, S. (2021). Moving forwards not backwards: heterogeneity in autism spectrum disorders. *Molecular Psychiatry.* https://doi.org/10.1038/s41380-021-01226-7

Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry, 55*, 80-89. https://doi.org/ 10.1016/j.eurpsy.2018.09.004

Lever, A. G., & Geurts, H. M. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020). “I wouldn’t know where to start”: perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism, 24*(4), 919-930.

Maisel, M. E., Stephenson, K. G., South, M., Rodgers, J., Freeston, M. H., & Gaigg, S. B. (2016). Modeling the cognitive mechanisms linking autism symptoms and anxiety in adults. *Journal of Abnormal Psychology, 125*(5), 692–703. https://doi.org/10.1037/abn0000168.

National Institute for Health and Care Excellence. (2016). Autism spectrum disorder in adults: Diagnosis and management [CG142]. Retrieved from: https://www.nice.org.uk/guidance/cg142

Pellicano, E., & den Houting, J. (2021). Annual research review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13534

Petty, S., Bergenheim, ML., Mahoney, G., & Chamberlain, L. (2021). Adapting services for autism: Recommendations from a specialist multidisciplinary perspective using freelisting. *Current Psychology*. https://doi.org/10.1007/s12144-021-02061-3

Spain, D., & Happé, F. (2020). How to optimise cognitive behaviour therapy (CBT) for people with autism spectrum disorders (ASD): a Delphi study. *Journal of Rational-Emotive & Cognitive-Behavior Therapy, 38*, 184–208. https://doi.org/10.1007/s10942-019-00335-1.

Uljarević, M., Richdale, A. L., McConachie, H., Hedley, D., Cai, R. Y., Merrick, H., Parr, J. R., & Le Couteur, A. (2018). The hospital anxiety and depression scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research, 11*(2), 258–269. https://doi.org/10.1002/aur.1872.

Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The interplay between sensory processing abnormalities, intolerance of uncertainty, anxiety and restricted and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(4), 943–952. https://doi.org/10.1007/s10803-014-2248-x.