

# *Lived experiences of depression in autistic children and adolescents: a qualitative study on child and parent perspectives*

Article

Published Version

Creative Commons: Attribution 4.0 (CC-BY)

Open Access

Rhodes, S. M., Eaton, C. B., Oldridge, J., Rodgers, J., Chan, S. ORCID: <https://orcid.org/0000-0003-4088-4528>, Skouta, E., McKechnie, A. G., Mackie, L. and Stewart, T. M. (2023) Lived experiences of depression in autistic children and adolescents: a qualitative study on child and parent perspectives. *Research in Developmental Disabilities*, 138. 104516. ISSN 1873-3379 doi: <https://doi.org/10.1016/j.ridd.2023.104516> Available at <https://centaur.reading.ac.uk/111975/>

It is advisable to refer to the publisher's version if you intend to cite from the work. See [Guidance on citing](#).

To link to this article DOI: <http://dx.doi.org/10.1016/j.ridd.2023.104516>

All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other copyright holders. Terms and conditions for use of this material are defined in the [End User Agreement](#).

[www.reading.ac.uk/centaur](http://www.reading.ac.uk/centaur)

**CentAUR**

Central Archive at the University of Reading

Reading's research outputs online



ELSEVIER

Contents lists available at ScienceDirect

# Research in Developmental Disabilities

journal homepage: [www.elsevier.com/locate/redevdis](http://www.elsevier.com/locate/redevdis)

## Lived experiences of depression in autistic children and adolescents: A qualitative study on child and parent perspectives

Sinead M. Rhodes<sup>a,b,\*</sup>, Christopher B. Eaton<sup>c</sup>, Jessica Oldridge<sup>d</sup>, Jacqui Rodgers<sup>e</sup>, Stella Chan<sup>f</sup>, Ereni Skouta<sup>g</sup>, Andrew G. McKechnie<sup>h</sup>, Leila Mackie<sup>i</sup>, Tracy M. Stewart<sup>j</sup>

<sup>a</sup> Child Life and Health, University of Edinburgh, UK

<sup>b</sup> Centre for Clinical Brain Sciences, University of Edinburgh, UK

<sup>c</sup> Division of Psychological Medicine and Clinical Neurosciences, MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University, Wales, UK

<sup>d</sup> Clinical Psychology, School of Health and Wellbeing, University of Glasgow, UK

<sup>e</sup> Population Health Sciences Institute, Faculty of Medical Sciences, Newcastle University, UK

<sup>f</sup> School of Psychology and Clinical Language Sciences, University of Reading, UK

<sup>g</sup> NHS CAMHS South London and Maudsley, Snowsfield Adolescent Unit, Maudsley Hospital, London, UK

<sup>h</sup> The Patrick Wild Centre, University of Edinburgh, UK

<sup>i</sup> NHS Paediatric Speech and Language Therapy Service, Lothian, UK

<sup>j</sup> Moray House School of Education and Sport, University of Edinburgh, UK

### ARTICLE INFO

#### Keywords:

Autism  
Depression  
Children  
Adolescents  
Parents

### ABSTRACT

**Background:** Depression is highly prevalent in autistic children and adolescents. Despite this, little is known about the nature of the autistic child's subjective experience of depression and the impact of depression on their lives.

**Methods:** We therefore conducted a qualitative study using thematic analysis with 7 autistic children and adolescents and their parents to identify common themes and individual differences. All children had previously experienced at least one depressive episode.

**Results:** Six main themes were identified: (1) Autism related experiences; (2) Difficulties with peer relationships; (3) Co-occurring relationships between anxiety and depression; (4) Impactful pessimism and anhedonia; (5) Impactful difficulties with focus and concentration and (6) Feelings of irritability, including aggressive behaviours. Parent's accounts of their children's experience of depression mirrored the child's perspective. Novel findings included reports of depression related restriction of diet variety and masking of mental health difficulties. Children and parents linked being autistic and developing depression, referring to the difficulties of being autistic in a complex, neurotypical world.

**Conclusions:** These results highlight key challenges that autistic children and their families experience, calling for increased awareness of the impact of depression on autistic young people.

\* Correspondence to: Child Life and Health & Centre for Clinical Brain Sciences, University of Edinburgh, Royal Hospital for Sick Children, 50 Little France Crescent, EH16 4TJ, UK.

E-mail address: [sinead.rhodes@ed.ac.uk](mailto:sinead.rhodes@ed.ac.uk) (S.M. Rhodes).

<https://doi.org/10.1016/j.ridd.2023.104516>

Received 1 November 2022; Received in revised form 22 February 2023; Accepted 19 April 2023

Available online 2 May 2023

0891-4222/© 2023 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

## 1. What does this paper add?

The paper findings highlight the lived experience of autistic young people in relation to their experience of depression. The findings highlight masking of mental health difficulties. They reveal a link between being autistic and developing depression and the difficulties of being autistic in a complex, neurotypical world.

Autism<sup>1</sup> is a lifelong neurodevelopmental difference that influences the way a person interacts and communicates with others and experiences the world around them and is characterised by the presence of restricted and repetitive behaviours. There is growing emphasis from researchers, clinicians and those with lived experience of autism that co-occurring mental ill-health is a significant issue for health, well-being and mortality. Simonoff et al. (2008) reported that 70% of autistic children<sup>2</sup> aged 10–14 years met diagnostic criteria for at least one co-occurring psychiatric diagnosis and 41% met criteria for two or more. These rates are much higher than for young people in the general population, with 20–25% experiencing a psychiatric disorder in a given year (Patel et al., 2007). Depression is one of the most common psychiatric conditions experienced by autistic people (Greenlee et al., 2016) with a recent systematic review of the child and adolescent autistic literature reporting rates of up to 83.33% (Stewart et al., 2021).

In the general population, depression is relatively uncommon in pre-pubertal children (1–2%) but prevalence rates begin to rise post puberty to around 4–5% by mid to late adolescence (Jane Costello et al., 2006), with a rapid six-fold increase from ages 15–18 years (Hankin & Abela, 2005). Adolescent depression has been shown to be a risk factor for a range of adverse outcomes including substance abuse, educational underachievement, interpersonal violence and unplanned pregnancies, and suicidal behaviours (McLeod et al., 2016). Depression is a heterogeneous disorder characterised by a wide range of symptoms including either (or both) anhedonia and low mood, alongside a range of cognitive, physiological, emotional and behavioural features (American Psychiatric Association [APA], 2013). Cognitive symptoms include for example difficulties with focused attention, memory, decision making, negative biases and completing schoolwork. Physiological symptoms include altered sleep and appetite. Emotional symptoms include sadness, feelings of emptiness, poor self-worth, guilt, self-blame, anger, and irritability. Behavioural symptoms include crying, fidgeting, and avoidance of social interactions.

Autism itself can be characterised by several of these features, for example social communication difficulties which can lead to social avoidance, dietary restrictions and cognitive difficulties. This may make it difficult to disentangle symptoms of depression from characteristics of autism. Many depression symptoms are also similar to key characteristics of ADHD, such as difficulties with memory, focusing, decision-making, and fidgeting (APA, 2013) and there is also a high rate of co-occurrence of autism and Attention Deficit Hyperactivity Disorder (ADHD), with as many as 34% of autistic people experiencing co-occurring ADHD (Lai et al., 2019). Given these overlaps, it is imperative we develop an understanding of autistic children's experiences of depression to help inform the identification, diagnosis and treatment of depression in this population. However, little is actually known about the lived experience of depression for autistic children.

Preliminary evidence suggests that anhedonia is the most powerful contributor to depression in autistic young people, whilst depressed mood, the other key symptom of depression, was only the fourth most powerful predictor (Bitsika & Sharpley, 2015). It is possible that depression follows a different pattern for autistic young people than for the general population where low mood is more prevalent than anhedonia (Rice et al., 2019). These putative differences in symptom profile may lead to poor case recognition and increased clinical risk for autistic people. Indeed, depression is a significant predictor of self-harm and suicidality (Hetrick et al., 2012). A meta-analysis found that autistic people were three times more likely to engage self-harm and suicide than the general population (Blanchard et al., 2021). This highlights the vital need to understand the nature and impact of depression for autistic children.

The current study adopted a qualitative approach to understand the experience and daily life impact of depression for autistic children and adolescents from their own perspective. In order to provide a comprehensive understanding of child depression, parents of the same children were also interviewed. In this study, we address the following questions: 1) What are autistic children's perspectives of their depression experiences? 2) What impact does depression have on the daily life experiences of autistic children? and 3) Do children and parents agree regarding the autistic children's thoughts about their depression?

**Table 1**  
Child Participant Characteristics.

Characteristic	Mean (Range)
Age	15.05 (9–18)
Age at autism diagnosis	6.42 (3–12)
SIMD	5.42 (4–10)
AQ-50 Parent	52.71 (22–115)
AQ-50 Child	30 (20–40)
CDI Parent	69.57 (53–89)
CDI Child	65.57 (43–90)
ADHD T Scores Conners Global Index	74.71 (58–90)
CAIDS-Q	5.42 (5–7)

## 2. Method

### 2.1. Participants

A total of 14 participants took part in the study including seven autistic children and adolescents whose parent reported their child had a current or previous history of depression (5 male, 2 female). See [Table 1](#) for descriptive statistics on key child participant characteristics. A parent of each of the children also took part (Mage = 47.67 range = 41–51; 6 mothers, 1 father). (“[Table 1](#)”).

Parents completed a questionnaire asking about background demographic information (age and gender of both parent and child), details about their child’s autism spectrum disorder diagnosis (name of diagnosis, who diagnosed the child, e.g. child psychiatrist, and age at diagnosis), whether the child had been diagnosed with another neurodevelopmental disorder (diagnosis, age at diagnosis and whether this or the ASD diagnosis came first) and whether the child had been diagnosed with a depressive disorder. Autism diagnosis was confirmed by all parents.

All participants had been diagnosed by paediatricians and child psychiatrists between the ages of 3 and 12. Child and parent participants completed a range of questionnaires to characterise the child sample as fully as possible. To measure autistic traits, parents completed the Autism Spectrum Quotient (AQ-50, [Baron-Cohen et al., 2001](#)) about their child, a 50-item screening questionnaire measuring behaviours relating to autism. Autistic young people aged 16–18 also completed the self-report version of this questionnaire. Parents of autistic participants and children completed the Children’s Depression Inventory, 2nd Edition ([Kovacs & Beck, 1977](#)) to measure depressive symptoms. One child had a co-occurring diagnosis of ADHD. 5 participants were diagnosed prior to the publication of DSM-V ([APA, 2013](#)), which for the first time allowed dual diagnosis of ASD and ADHD. All participant’s parents completed the Conners Parent 110 item rating scale. All of the children scored above the ADHD threshold with 6 of the participants having T score > 65 on the Connors Global Index indicating elevated scores. To confirm the absence of an intellectual disability, parents completed the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q, [McKenzie et al., 2019](#)). This questionnaire asks about basic functional skills, literacy and previous support from clinical and educational services. All children scored above the threshold on this measure where scoring above 5 indicates the young person is unlikely to have an intellectual disability.

All families recruited were based in the UK. Socio-economic status was evaluated using the Scottish Index of Multiple Deprivation (SIMD) based on current postcode. A score of 10 indicates the least deprived 10% of the population, and 1 the most deprived 10%, showing our sample came from average to low deprivation areas.

### 2.2. Procedure

Participants were recruited from charities in Scotland and through social media. Participants were included in the study if they met the following criteria: were aged between 8 and 18 years, had a confirmed diagnosis of autism and depression by their parent. Exclusion criteria included having an intellectual disability as assessed by the CAIDS-Q screening measure. ID was an exclusionary criterion as research has shown that depression is characteristically different in those with ID ([Hermans & Evenhuis, 2010](#); [Magnuson & Constantino, 2011](#)). Parents and autistic young people each received a £ 20 voucher for taking part. There were no exclusion criteria for parents.

Both children and their parents took part independently in semi-structured interviews where they completed a depression questionnaire (child and parent version) developed by the research team. These questionnaires were designed as part of the initial development of a new ‘Neurodevelopmental depression Inventory’; a broader study involving a larger sample (i.e. including autistic children without depression) to co-produce a newly developed Inventory with young autistic people and their families. The questionnaire contained 24 items including the items included in depression measures developed for the general population, e.g. physiological items (e.g. I slept more), behavioural (e.g. I was fidgety and moved around more than usual), cognitive (e.g. I couldn’t focus as well as usual) and emotional (e.g. I was annoyed) related items. We also included an autism specific item relating to diet (“I ate fewer types of food than usual”).

In the current reported study, the children with a history of depression and their parents were interviewed about their personal experience of each of these 24 items (i.e. depression symptoms) in the questionnaire. They were asked what they (or their child) thought, felt or did in relation to each item e.g. ‘I was sad’ when they were depressed. We also asked each participant and their parent if there was anything else they experienced when they were depressed. Participants took part in a post-assessment where they provided ratings of their mood pre and post watching soothing images from ‘Project Soothe’ ([Wilson et al., 2018](#)). This step was included as a way of reducing any potential distress caused by participation in a study that may have raised sensitive issues around the lived experience of depression. Data were collected in-person or online during June to December 2020, which included times of COVID-19 restrictions. This study was approved by (Moray House School of Education and Sport Ethics Committee) Ethics Committee.

### 2.3. Data analysis

The selection of qualitative methodology locates the children and parents with lived experiences of autism as central to exploration and uncovering of their meanings and experiences (Lyons and Cole, 2021). Therefore, the authors as researchers who analysed the data (SR and TS) engaged in an empathic interpretivist stance ([Willig, 2012](#)). The positionality of the researchers also incorporates a substantive history of professional experience with autistic children and adults, and a theoretical alignment with the biopsychosocial framework of disability. The International Classification of Functioning, Disability and Health (ICF) ([WHO, 2001](#)) recognises the influence of social models of disability and the advocacy for disability rights disability but also frames disability as the interaction

between an individual's impairment, functioning and environment.

Reflexive thematic analysis (Braun & Clarke, 2006, 2013, 2019) was used to analyse the data on depression experiences. This approach was chosen as rather than holding the researchers to a specific framework, it allows the researchers to engage in a theoretically flexible interpretative approach. Thematic analysis facilitates the identification and analysis of patterns in the dataset and offers the ability to develop rich and detailed analysis. Thematic analysis has been identified as particularly suited to analysis of lived experience data (Braun, Clarke, Hayfield & Terry, 2019).

The analysis involved the following 6 stages: (1) familiarisation with the data, (2) generation of initial codes, (3) identification of themes, (4) review of themes, (5) definition of themes and (6) paper production. The analyses were led by author SR, in consultation with author TS taking a collaborative and reflexive approach. Author SR conducted steps 1–4 and then reviewed the work produced by these stages with author TS. For the familiarisation process, author SR read the transcribed data in full several times to enable opportunities for reflexivity. Casual notes were taken through the process. At the point the author appraised they were at the stage of being fully immersed in the data, work began on generating initial codes. The initial codes identified were subsequently revised particularly those that were deemed semantic. Some initial codes were split into two different codes. This followed an organic and open iterative process (Braun et al., 2019). In line with reflexive thematic analysis, themes were identified from meaning-based patterns linked back to the 3 research questions. Author TS independently read the transcribed data in full. The authors discussed the themes and they were reviewed, revised and extended. The wider team of authors also met and discussed the themes. Discussion included reviewing of themes to make sure the data related to a key organised concept and careful attention was paid to potential overlaps between the content of themes. The themes generated resulted from considerable analytic work that followed a reflexive process and was ongoing from initial reading of the transcripts to revision of themes following discussion of the researchers. Author SR then completed the final two steps (5–6). While in some cases children and their parents held differing views / experience perceptions, in general their experiences converged and it was decided to take a multi-informant approach common in the literature (e.g. Halsall et al., 2021).

### 3. Results

Six main themes were identified from the interview data: (1) Autism related experiences; (2) Difficulties with peer relationships; (3) Co-occurring relationships between anxiety and depression; (4) Impactful pessimism and anhedonia; (5) Impactful difficulties with focus and concentration and (6) Feelings of irritability, including aggressive behaviours.

#### 3.1. Theme 1: Autism related experiences

A theme that emerged from the data were experiences related to being autistic. Children almost universally reported that they restricted their diet in relation to the types of food they ate further when they were experiencing low mood. For example, one child said: *"I used to eat so many types, like pasta, tomato soup. But ever since I was sad, I don't, I have gone off it so much"*. Others referred to reasons for their restricted diet: *"it was a less varied diet for me. I couldn't really be bothered cooking so I kind of maybe just ate like simple things I would buy from the shop and that didn't take much effort"*. Other children noted that they wanted to eat the same kind of meals every day when depressed but weren't aware they were doing so at the time, referring to their mother having spoken about it.

Parents also reported children eating fewer types of food as a feature of their child's depression. A parent referred to their child as: *"being less open to eating and maybe the variety they would have"*, while another said: *"he gets more restrictive if he feels sadder"*. One parent referred to depression having caused restrictions across their child's life including diet: *"depression has definitely self-restricted his whole life, and his diet definitely got narrower"*.

One of the child participants referred to 'stimming more' indicating increased repetitive behaviours such as pacing when depressed, but linked the cause of this to the accompanying anxiety they experienced when depressed.

Several parents mentioned sensory overload and its relationship to depression. One parent linked their child being withdrawn with *"the sensory overload of people"* and commented that the child often missed days off school because of sensory overload.

On a more general level, child participants perceived that being autistic was linked to depression *"it (autism) can cause problems in your life that you may never be able to fix"*. Reference was made by some children to not engaging in observable behaviours linked to depression and one child related this to being autistic *"I'm not really a person to cry. Probably I think it's probably less so with autistic people"*.

Hiding signs of depression was also mentioned by parents *"my son doesn't tend to cry so if he does, it's really like a big deal, I can see him fighting back tears and kind of controlling and it's rare, he was crying this afternoon, it's rare, I can almost count on my hands the number of times he'll cry in a year, so again masking"*. A parent echoed children linking autism to depression *"I guess it's the norm for him to be feeling low because it can be a hostile difficult world to navigate if you have autism"* and another said she perceived her son to feel pessimistic because he thinks *"my autism won't change so how can anything be different"*. Another parent linked depression to isolation associated with being autistic *"Autistic kids get left behind and isolated. Or self-isolate to protect themselves. I know the link between autism and depression is very high and I think it's to do with that"*.

#### 3.2. Theme 2: Difficulties with peer relationships

Children and their parents described depression-related difficulties with peers. Children referred to needing to hide depression symptoms from their peers (e.g. *"you don't want your friends to pick up on it [depression]"*) and *"because of the guilt and stuff that comes with depression happening there's a level of you that doesn't want to see your own friends because they might not think you're the same person"*. One

young person suggested depression had changed them as a person in relation to their friends (e.g. *“very much for me personally was just I knew that I was a very different person because of depression”*) with others stating that they wanted to protect their friends from risks perceived from interacting with someone with low mood: *“you might not know how you’ll react or anything and you can’t say how well the day is going to go and so you don’t want to put your friends or people you care about at risk”*.

Some children referred to losing contact with their friends (e.g. *“I did lose contact with a few of my friends”*) with others saying they stopped contact with their friends when they felt depressed (e.g. *“I kind of stopped responding, then she got a bit annoyed and she thought that I didn’t want to be friends with her anymore”*). Another child described how they didn’t want to lose the friendship but rather put a pause on contact during this time: *“it wasn’t so much that I didn’t want to see them or I didn’t want to be friends with them anymore, I just didn’t feel like responding to them and needing a break from them”*. Reconnecting with friends once feeling better was also difficult for some children e.g. *“it was kind of hard to get back in contact again. For a while there was people who would send messages but I just didn’t feel like so I just kind of left them. Then the longer you do that the harder it is to get back to them”*.

These depression-related peer difficulties were echoed by children’s parents. Difficulties in sustaining and maintaining relationships during depressive episodes were highlighted e.g. *“well actually during that whole depressive period, really during the whole of secondary [school] he has found it hard to make friends or to keep friends because of the depression”* and *“the gulf between him and his peers just keeps widening and widening and he really wants to have friends but he doesn’t have”* and *“he doesn’t have any friends, he has ‘mutuals’ a word he uses on gaming which are acquaintances. It’s a very sensitive one, he’s decided he doesn’t want friends”*.

Other parents referred to social situations leading to their child overthinking (e.g. *“there might be an interaction outside the home with people and they then come back and think about every aspect of what happened”*) while others referred to, what they believed, enabled their child’s depression symptoms. One parent said the *“biggest reason for his depression is his interaction with his peers”*, while another said *“he’s been bullied for that [appearance] before and it lead to his depression”*.

Parents also referred to the drop in contact with friends when their child was feeling low. One parent said *“she doesn’t want to see her school friends”* and also referred to reduced social media contact with friends *“she couldn’t deal with social media so she just took a break from it, so yeah there were times when she didn’t want to see her friends in a social media setting”*. This in-person and online withdrawal was reflected on by another parent *“he doesn’t even want to go online on his computer with them”*. One parent commented their child put a function on their computer game so their friends could not see they were online when experiencing a low mood. Another parent said *“he’s definitely retreated a lot into the iPad and things, instead of like going to the Yard (an activity place for children with developmental difficulties). A lot of those things disappeared when he was anxious and depressed”*. Other parents referred to their child hiding their symptoms of depression from their peers.

### 3.3. Theme 3: Co-occurring relationships between anxiety and depression

A third theme identified related to feelings of anxiety that co-occurred with depression. Anxiety was consistently mentioned by children and their parents as a significant area of difficulty. Children commented that feelings of depression and anxiety overlapped e.g. *“I felt the root cause of my depression was kind of anxiety”* and another said *“I think a lot of my depression was because of being anxious so I’d be too busy thinking about something irrelevant rather than focusing on the actual thing I should be anxious about, so I’d be stressing about something that might happen in the future rather than failing schoolwork for example, which is much closer and a more realistic problem”*.

Parents also described anxiety in their children when depressed and its impact on everyday activities. For some, anxiety was related to sleep difficulties e.g. *“I would say he has problems sleeping at night because of anxiety because he can’t get to sleep”*. Anxiety was also linked to being able to feel enjoyment and to engage in activities e.g. *“depression and anxiety can really interfere with the things he wants to enjoy”* and another commented that anxiety, as well as depression, contributed to their child stopping several hobbies *“he had to stop.... partly because he was bringing the depression and anxiety into those other hobbies”*.

Anxiety was also mentioned in relation to social interactions e.g. *“it was the anxiety that started before he left the house, the anxiety in the taxi on the way to school, entering the school playground”*. One parent referred to a relationship between being anxious and a perceived concern that their behaviour was aggressive or inappropriate *“he thinks he is being aggressive or cross or being inappropriate but he’s not actually showing that to others. So it’s very internalised but he often has a major anxiety about the fact that he might be being inappropriate or aggressive”*.

In the more general sense, anxiety about the future was linked to the cause of depression *“depression and anxiety can really interfere with the things he wants to enjoy”*. Another parent linked anxiety with feeling pessimistic *“the anxiety kicks in and it just feels like how do you ever do anything to improve the situation that you’re in”* and *“I think he has quite low self-esteem so I think he has a problem in seeing how he could contribute to society”*.

### 3.4. Theme 4: Impactful pessimism and anhedonia

Pessimism and anhedonia were commonly characterised by children and parents as being impactful. Examples from children included *“I definitely felt like that in the past, like what’s going to happen next?”* and *“I think it was personally the idea that the negatives outweigh the positives”*. One child linked pessimistic feelings to the cause of depression *“yeah definitely that was almost the root cause”*.

Parents shared similar perspectives *“I think they have a less positive view of things”* and offered the explanation that *“everything’s just such hard work for them to fit in and to see the future as rosy”*. Another parent said *“when he’s in that bad place or when he’s been in that bad place, he will think everything is pointless like what’s the point, so when life becomes pointless, my interpretation of that is that he doesn’t think there is anything good for him in the future”*.

A lack of enjoyment in activities during depressive episodes was highlighted by many of the children as impacting them e.g.



“sometimes I feel like I can't really enjoy things that much”. There was heterogeneity in responses though with one child describing the opposite pattern “the things I enjoy are my escape from it (depression)”. Differences between participants in enjoying activities was exemplified in relation to reading books. Several children said reading was a distraction they would engage in more when depressed to take their mind off their low mood e.g. “The only thing I did was kind of read books which I did before, that's kind of an escapism thing rather than just something I find fun”. Others referred to not reading during those times and losing interest in their hobbies e.g. “the occasional time you do find a bit of enjoyment in something but it becomes so infrequent that you kind of forget what it is to enjoy like things”.

Parents shared similar perspectives e.g. “he would say mum I know I've supposed to have enjoyed that, I would have normally have enjoyed you know if we went to the zoo or the cinema but I felt I couldn't enjoy it” and the parent interpreted this as caused by overthinking and worrying. Another parent said that depression and anxiety really interfered with what their child wants to enjoy.

### 3.5. Theme 5: Focus and concentration

There was a common commentary surrounding a lack of focus and concentration which contributed to disengagement with day to day tasks or finding activities enjoyable. Children spoke about having difficulty in concentrating when depressed e.g. “I Just feel like I can't focus” and this child mentioned focusing on things a lot that were stressing him out and it effecting being able to focus on things he needed to. Another child similarly echoed “you've got so many thoughts going on at once even just trying to focus on one thing becomes impossible”. Children offered explanations for difficulty in focusing in relation to both motivation and fatigue. Several discussed how overthinking and stressing about social situations meant they had little energy for things like school-work or hobbies – “you are just too tired to complete your normal tasks” and another referred to “not being able to focus in the sense of not being able to channel your thoughts”. Another child commented “I really fell behind in my school-work” when talking about difficulties focusing when depressed.

Parents also emphasised a link between stress and focus e.g. “I know that at school if he's stressed or down about the social side of things, that is all he's thinking about, he'll not focus on work”. There was also a suggestion that preoccupation with thoughts was impacting focus and the ability to then engage in daily life activities “he's distracted because he's got thoughts or other things going on in his head” and “he's very preoccupied with his thoughts, he almost can't engage with what's going on in the world” and “It felt as though the focus was inwards and all the focus was just an inwards thing he couldn't focus on reading or his artwork he just couldn't apply himself to anything”. Another parent linked their child's pre-occupation with their thoughts as the reason for not enjoying things they normally enjoy.

### 3.6. Theme 6: Irritability and aggression

Irritability, anger and aggression were characterised by children in relation to their depressive episodes. One child commented they expressed anger outwards “sometimes I just feel like getting I don't know I just feel like kicking off and I don't know, sometimes I punch walls” but also inwards “I even think about doing something like spraying the air freshener in my eyes”. Another commented they felt these feelings towards themselves “there's a lot in terms of being annoyed at yourself and your own actions”. Others were annoyed with peers “I was annoyed at all the people in my school, there was only a few people I didn't (feel annoyed at)”.

Parents referred to their children expressing irritability within the home context “He would feel very unhappy with things that were going on in his life. When he was sad it would display in different ways. You know, angry with people, the world” and another said that when depressed their child had “more mood swings and was more violent with the anger”. Anger was also commented on as directed at siblings “he was very violent towards his younger sister. He'd come home and whatever had gone wrong in school was her fault, being aggressive and violent. And then would get very upset about the whole thing”. Parents described the impact of these feelings “he gets annoyed at the simplest of things, you've got to take him off of games because if he's feeling that way the world is against him” and another said “he used to do horse riding and we had to stop because he was kicking the horse, getting angry at everything”. The relationship of irritability to depression and autism were described as different “he does quite often get quite irritated because of his autism because he sometimes doesn't understand things or he feels he's misunderstood but actually it's a separate thing to when he gets irritated when he's depressed because when he's irritated when he's depressed it adds an extra layer of depression and upset”.

## 4. Discussion

This qualitative study of child and parent perspectives of autistic children and adolescents experiences of depressive episodes has yielded novel insights. Some of the themes were linked specifically to autistic characteristics such as further restricting the types of food eaten and sensory overload. Other themes related to anxiety, lack of focus and pessimism and anhedonia impacting daily life, and experiences of irritability that are consistent with depression experience in the general child population. This study has described the impact of depression on young autistic people and particularly the effects on daily life in home and education settings. Children and their parents converged on their perception of the child's experiences with parents providing additional insightful examples. Research with children and young people in relation to the experience of depression is particularly important given the earlier presentation of symptoms in this sample.

A core aim of this study was to gain insight into autistic children's perspectives of their depression experiences. One of the most important insights was the emphasis made on difficulties with relationships as central to autistic children's depression experiences. This finding is in keeping with a recent systematic review that reported that rejection and peer victimisation was common in autistic adolescents (Cresswell et al., 2019). Families in our study indicated peer relationship challenges were often the cause of the child's depression. Some linked social isolation and withdrawal to contributing to depression, while for others peer relationship challenges including bullying was inferred to have caused the depression. Our findings suggest that having a depressive episode led most children



to withdraw further. These findings are important because we know that social connectedness and peer support is a protective factor against mood disorders (Pfeiffer et al., 2011). A lack of connection to others can have negative consequences for physical and mental health, as well as increased mortality (Caspi et al., 2006; Hawkey & Cacioppo, 2010; Orben et al., 2020).

A common statement was that the child was aware they were acting differently and didn't want their peers to see this, either because they would worry or for fear they could harm them. Children and their parents reported hiding, and some referred to 'masking', their depression symptoms. This echoes findings that half of young people in the general population expressed that they would feel embarrassed by having a mental health diagnosis and fear they would be treated differently (YouGov/MQ and Forster, 2016). It is now well documented that masking of autistic characteristics is highly prevalent within the autistic community (Halsall et al., 2021) and is associated with mental health difficulties (Hull et al., 2021). We found that children often tried to hide signs of their depression from their peers and parents which potentially contributes to the negative effects of masking on autistic children's mental health and wellbeing. Children described their efforts to hide their own depressive symptoms as causing fatigue potentially exacerbating the severity or continuation of these symptoms. Research on masking to date with autistic children has focused on autistic traits. Our findings suggests additional masking of mental health difficulties and further research is needed to investigate this 'double whammy'. These findings are in line with studies reporting on how autistic young people try to manage difficult emotions, such as engaging in avoidance and isolation strategies to deal with difficult emotions, and suppressing behavioural output of emotions to hide it from others Santomauro et al. (2017). The negative consequences of these strategies included difficulties forming strong social relationships, which in turn could further exacerbate low mood and feelings of isolation and rejection. While the current study's findings are preliminary, they highlight the need for further research to investigate the relationship between depression and peer relations in autism.

There were aspects of the experiences described by autistic participants that map on to ways in which depression is described by neurotypical children. For example, changes to appetite when experiencing depression. Participants were asked about an autism specific item regarding eating fewer types of food when depressed, referring to the restricted diet autistic children often have. Children almost universally reported that they further restricted their diet when they experienced low mood. These findings suggest that low mood is not only associated with altering quantity of food eaten, but also restriction of diet variety within the context of an already restricted diet. While change in appetite is one of the diagnostic criteria for depression (APA, 2013), diet restriction has not been reported before in the literature. These findings suggest that it may be a clinical indicator of depression possibly linked to an increase in restricted and repetitive behaviours more generally in response to low mood in autistic young people. Further research with a larger and more representative sample is warranted to investigate this further. The sensory overload experienced in social contexts was linked to withdrawal from social situations and parents suggested this increased isolation was associated with the cause of depression. In general, children and parents saw a connection between being autistic and developing depression, referring to the difficulties of being autistic in a complex, neurotypical world.

Anxiety was suggested by both children and their parents as being related to and often causing depression. Co-occurrence of anxiety and depression is well established in the general population (Garber & Weersing, 2010). Our findings supports Ozsivadjian et al. (2012) who found autism specific triggers for anxiety including routine change, sensory sensitivities, as well as social triggers such as difficulties with perspective taking and social expectations, with symptoms encompassing challenging behaviour, avoidance, withdrawal and a difficulty with expressing anxiety verbally.

Similar to the experience in the general population, anhedonia and pessimism for the future were strongly emphasised as significantly impacting autistic young people. A lack of motivation combined with fatigue was associated with focusing on negative situations and interactions and at the same time not being able to concentrate on everyday tasks such as school work and hobbies. Several mentioned withdrawing from social interactions and activities because of their anxiety. In turn, such withdrawal and lack of engagement was associated with greater depression risk, a link well established in the general population (Strauss et al., 1986; Vargo, 1996). Pre-occupation with thoughts was linked to not being able to focus or concentrate on everyday life activities, suggesting that rumination is a common experience of depression both in autistic and general populations (Watkins & Baracaia, 2002). Children had high levels of ADHD symptoms but discussions around focusing tended to centre on the link to pre-occupied thoughts. We found that many of the symptoms of poor mental health are inter-related in this population.

Irritability is a diagnostic characteristic of depression exclusive to children and adolescents (APA, 2013). In this study, autistic participants frequently mentioned things that annoyed or angered them, such as their peers. Increased feelings of annoyance or being easily irritated by others is both a feature of typical adolescent development, and of childhood depression (APA, 2013). It is therefore unsurprising for this to feature heavily in the experiences of autistic youth with depression. This association between irritability and depressive symptoms may be more profound in this population. A large cohort study (Eyre et al., 2019, pp. 13053) found that the link between irritability and depressive symptoms was higher in the autistic sample. Irritability scores explained 51% of the association between social communication difficulties and depression scores.

In general, children and their parent's converged on the child's experience of depression which contrasts to parents and adolescents within the general population (Orchard et al., 2019). For many of the issues mentioned such as the relationship between depression and being autistic, the difficulties of peer relationships, anxiety and anhedonia parents concurred with the child's experience providing more in-depth examples of these issues. Inclusion of parents alongside children undoubtedly enabled us to generate a richer dataset. The convergence we report is similar to the consistency observed between the perspectives of autistic young people and their parents in studies exploring camouflaging (Halsall et al., 2021), emotion regulation difficulties (Santomauro et al., 2017), and anxiety (Ozsivadjian et al., 2012) in autism.

While our study has addressed a gap in the literature relating to the lived experience of autistic young people in relation to their experience of depression, there are a number of limitations which should be addressed in further research. While we obtained novel

and rich lived experience data, the sample size was relatively small and we included a fairly broad age range of children and adolescents. The participant's varied in the nature of their lived experience, how independent they were in relation to age, and the depth of their responses as a result. With evidence of high rates of depression in this population during childhood and adolescence (Stewart et al., 2021) it is important that future research includes larger samples sufficient to explore the emergence of depression in autistic young people. The relationship between depression and autism alongside co-occurring anxiety is very complex and caution needs to be taken in the interpretation of findings in this regard. Despite the high prevalence and earlier presentation of depression in autistic young people reported in the literature, research examining lived experience is sparse and warrants further attention.

Whilst the presence of a depressive disorder diagnosis was ascertained through a parent questionnaire, this was not confirmed directly with a clinician. We also did not ascertain whether the participants were currently experiencing a depressive episode. We should note that data were collected in-person or online during June to December 2020, which included times of COVID-19 restrictions. Whilst there is some evidence of worsening mental health for autistic children during the pandemic (Vasa et al., 2021), given the cross-sectional nature of the current study, it is not known if the pandemic impacted levels of depression specifically for participants in the current study.

As well as highlighting the experiences of depression and its impact depression on the lives of autistic young people, our study also has implications for the assessment of depression and use of neurotypically normed depression assessment tools in research. Findings suggest that autistic children may experience qualitative differences in depression characteristics to their neurotypical peers highlighting the need for the development of mental health tools that capture the experience of depression for these young people while focusing on identifying changes in behaviours that are features of neurodevelopmental conditions.

## 5. Conclusion

This study has identified convergence of child and parent perspectives on depression experiences in autistic young people and has highlighted several key themes about the triggers, manifestation and impact of depression in this population. The relationship between challenging peer relationships and depression and autistic young people's attempt to hide depressive symptoms to their friends was highlighted. A change in autism-related behaviours when depressed was noted such as further restrictions to the variety of food eaten. The role of co-occurring anxiety was reported when discussing the onset of depression and behavioural change during depressive episodes. Anhedonia and pessimism about the future were often reported as impacting daily life, as were difficulties with focus and concentration. Irritability and aggression were commonly described as features of depressive episodes. Further quantitative and qualitative studies exploring the experience, presentation and impact of depression for autistic young people are warranted to help inform better understanding, more accurate diagnostic tools and targeted interventions.

## Funding

This study was funded by the Salvesen Mindroom Research Centre, University of Edinburgh.

## CRedit authorship contribution statement

SR, JR, SC, ES, AM and TS were involved in the initial design of the study and secured the funding to run the study. CE was involved in further refinements to the study design alongside SR, JR, SC, ES, AM and TS. CE and JO were involved in data acquisition. SR analysed the data. SR wrote the first draft of the paper and all authors contributed to substantive revisions.

## Data Availability

The authors do not have permission to share data.

## Acknowledgements

This study was funded by the Salvesen Mindroom Research Centre, University of Edinburgh, There are no conflicts of interest to disclose. The funder played no role in the design or execution of the study or journal choice. We thank Dr Allan Piper who was involved in data collection for the current study as part of a National Training programme.

## Conflicts of Interest

There are no conflicts of interest to declare.

## References

- American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.). (<https://doi.org/10.1176/appi.books.9780890425596>).
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5–17. <https://doi.org/10.1023/A:1005653411471>

- Bitsika, V., & Sharpley, C. (2015). Differences in the prevalence, severity and symptom profiles of depression in boys and adolescents with an autism spectrum disorder versus normally developing controls. *International Journal of Disability, Development and Education*, 62(2), 158–167. <https://doi.org/10.1080/1034912x.2014.998179>
- Blanchard, A., Chihuri, S., DiGiuseppi, C., & Li, G. (2021). Risk of self-harm in children and adults with autism spectrum disorder. *JAMA Network Open*, 4(10), Article e2130272. <https://doi.org/10.1001/jamanetworkopen.2021.30272>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. <https://doi.org/10.1080/2159676x.2019.1628806>
- Caspi, A., Harrington, H., Moffitt, T., Milne, B., & Poulton, R. (2006). Socially isolated children 20 years later: Risk of cardiovascular disease. *Archives of Pediatrics & Adolescent Medicine*, 160(8), 805. <https://doi.org/10.1001/archpedi.160.8.805>
- Cresswell, L., Hinch, R., & Cage, E. (2019). The experiences of peer relationships amongst autistic adolescents: A systematic review of the qualitative evidence. *Research in Autism Spectrum Disorders*, 61, 45–60. <https://doi.org/10.1016/j.rasd.2019.01.003>
- Eyre, O., Hughes, R., Thapar, A., Leibenluft, E., Stringaris, A., Davey Smith, G., et al. (2019). Childhood neurodevelopmental difficulties and risk of adolescent depression: The role of irritability. *Journal of Child Psychology and Psychiatry*. <https://doi.org/10.1111/jc>
- Garber, J., & Weersing, V. R. (2010). Comorbidity of anxiety and depression in youth: Implications for treatment and prevention. *Clinical Psychology: Science and Practice*, 17(4), 293–306. <https://doi.org/10.1111/j.1468-2850.2010.01221.x>
- Greenlee, J., Mosley, A., Shui, A., Veenstra-VanderWeele, J., & Gotham, K. (2016). Medical and behavioral correlates of depression history in children and adolescents with autism spectrum disorder. *Pediatrics*, 2, S105–S114. <https://doi.org/10.1542/peds.2015-2851i>, 137(Supplement).
- Halsall, J., Clarke, C., & Crane, L. (2021). ‘Camouflaging’ by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. *Autism*, 25(7), 2074–2086. <https://doi.org/10.1177/13623613211012819>
- Hankin, B., & Abela, J. (2005). Depression from childhood through adolescence and adulthood: A developmental vulnerability and stress perspective. In B. L. Hankin, & J. R. Abela (Eds.), *Development of psychopathology: A vulnerability-stress perspective* (pp. 245–288). SAGE Publications, Inc. (<https://www.doi.org/10.4135/9781452231655.n10>).
- Hawley, L., & Cacioppo, J. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annals of Behavioral Medicine*, 40(2), 218–227. <https://doi.org/10.1007/s12160-010-9210-8>
- Hermans, H., & Evenhuis, H. M. (2010). Characteristics of instruments screening for depression in adults with intellectual disabilities: Systematic review. *Research in Developmental Disabilities*, 31(6), 1109–1120. <https://doi.org/10.1016/j.ridd.2010.04.023>
- Hetrick, S., Parker, A., Robinson, J., Hall, N., & Vance, A. (2012). Predicting suicidal risk in a cohort of depressed children and adolescents. *Crisis*, 33(1), 13–20. <https://doi.org/10.1027/0227-5910/a000095>
- Hull, L., Levy, L., Lai, M., Petrides, K., Baron-Cohen, S., Allison, C., et al. (2021). Is social camouflaging associated with anxiety and depression in autistic adults. *Molecular Autism*, 12(1). <https://doi.org/10.1186/s13229-021-00421-1>
- Jane Costello, E., Erkanli, A., & Angold, A. (2006). Is there an epidemic of child or adolescent depression? *Journal of Child Psychology and Psychiatry*, 47(12), 1263–1271. <https://doi.org/10.1111/j.1469-7610.2006.01682.x>
- Kovacs, M., & Beck, A. T. (1977). An empirical clinical approach towards a definition of childhood depression. In J. G. Schulterbrandt, & A. Raskin (Eds.), *Depression in children: Diagnosis, treatment, and conceptual models*. New York: Raven Press.
- Lai, M., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., et al. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819–829. [https://doi.org/10.1016/s2215-0366\(19\)30289-5](https://doi.org/10.1016/s2215-0366(19)30289-5)
- Magnuson, K. M., & Constantino, J. N. (2011). Characterization of depression in children with autism spectrum disorder. *Journal of Developmental and Behavioural Paediatrics*, 32(4), 332–340. <https://doi.org/10.1097/DBP.0b013e318213f56c>
- McKenzie, K., Murray, G., Murray, A., Delahunty, L., Hutton, L., Murray, K., & O'hare, A. (2019). Child and adolescent intellectual disability screening questionnaire to identify children with intellectual disability. *Developmental Medicine & Child Neurology*, 61(4), 444–450. <https://doi.org/10.1111/dmnc.13998>
- McLeod, G., Horwood, L., & Fergusson, D. (2016). Adolescent depression, adult mental health and psychosocial outcomes at 30 and 35 years. *Psychological Medicine*, 46(7), 1401–1412. <https://doi.org/10.1017/S0033291715002950>
- Orben, A., Tomova, L., & Blakemore, S. (2020). The effects of social deprivation on adolescent development and mental health. *The Lancet Child & Adolescent Health*, 4(8), 634–640. [https://doi.org/10.1016/s2352-4642\(20\)30186-3](https://doi.org/10.1016/s2352-4642(20)30186-3)
- Orchard, F., Pass, L., Cocks, L., Chessell, C., & Reynolds, S. (2019). Examining parent and child agreement in the diagnosis of adolescent depression. *Child and Adolescent Mental Health*, 24(4), 338–344. <https://doi.org/10.1111/camh.12348>
- Ozsvadjian, A., Knott, F., & Magiati, I. (2012). Parent and child perspectives on the nature of anxiety in children and young people with autism spectrum disorders: a focus group study. *Autism*, 16(2), 107–121. <https://doi.org/10.1177/1362361311431703>
- Patel, V., Flisher, A., Hetrick, S., & McGorry, P. (2007). Mental health of young people: A global public-health challenge. *The Lancet*, 369(9569), 1302–1313. [https://doi.org/10.1016/s0140-6736\(07\)60368-7](https://doi.org/10.1016/s0140-6736(07)60368-7)
- Pfeiffer, P., Heisler, M., Piette, J., Rogers, M., & Valenstein, M. (2011). Efficacy of peer support interventions for depression: A meta-analysis. *General Hospital Psychiatry*, 33(1), 29–36. <https://doi.org/10.1016/j.genhosppsych.2010.10.002>
- Rice, F., Riglin, L., Lomax, T., Souter, E., Potter, R., Smith, D. J., Thapar, A. K., & Thapar, A. (2019). Adolescent and adult differences in major depression symptom profiles. *Journal of Affective Disorders*, 243, 175–181. <https://doi.org/10.1016/j.jad.2018.09.015>
- Santomauro, D., Sheffield, J., & Sofronoff, K. (2017). Investigations into emotion regulation difficulties among adolescents and young adults with autism spectrum disorder: A qualitative study. *Journal of Intellectual and Developmental Disability*, 42(3), 275–284. <https://doi.org/10.3109/13668250.2016.1236240>
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921–929. <https://doi.org/10.1097/chi.0b013e318179964f>
- Stewart, T., Martin, K., Fazi, M., Oldridge, J., Piper, A., & Rhodes, S. (2021). A systematic review of the rates of depression in autistic children and adolescents without intellectual disability. *Psychology and Psychotherapy: Theory, Research and Practice*. <https://doi.org/10.1111/papt.12366>
- Strauss, C., Forehand, R., Smith, K., & Frame, C. (1986). The association between social withdrawal and internalizing problems of children. *Journal of Abnormal Child Psychology*, 14(4), 525–535. <https://doi.org/10.1007/bf01260521>
- Vargo, B. (1996). Are withdrawn children at risk. *Canadian Journal of School Psychology*, 11(2), 166–177. <https://doi.org/10.1177/082957359601100221>
- Vasa, R. A., Singh, V., Hologue, C., Kalb, L. G., Yang, Y., & Keefer, A. (2021). Psychiatric problems during the COVID-19 pandemic in children with autism spectrum disorder. *Autism Research*, 14(10), 2113–2119. <https://doi.org/10.1002/aur.2574>
- Watkins, E., & Baracaia, S. (2002). Rumination and social problem-solving in depression. *Behaviour Research and Therapy*, 40(10), 1179–1189. [https://doi.org/10.1016/s0005-7967\(01\)00098-5](https://doi.org/10.1016/s0005-7967(01)00098-5)
- World Health Organization. (2001). *The International Classification of Functioning. Disability and Health: ICF*. Geneva: WHO.
- Willig, C. (2012). *Qualitative Interpretation and Analysis in Psychology*. Maidenhead: Open University Press.
- Wilson, A., Schwannauer, M., McLaughlin, A., Ashworth, F., & Chan, S. (2018). Vividness of positive mental imagery predicts positive emotional response to visually presented Project Soothe pictures. *British Journal of Psychology*, 109(2), 259–276. <https://doi.org/10.1111/bjop.12267>
- YouGov/MQ and Forster (2016) Mental illness research: Children, April 2016 as quoted in MQ (2016) *The MQ Manifesto for Young People's Mental Health*. Available at: (<https://www.mqmentalhealth.org/wp-content/uploads/MQManifestoforyoungpeoplesmentalhealth2017.pdf>) [Accessed on 13 January 2022].