

Miller, Danielle, Rees, Jon and Pearson, Amy (2021) "Masking Is Life": Experiences of Masking in Autistic and Nonautistic Adults. Autism in Adulthood. ISSN 2573-959X

Downloaded from: http://sure.sunderland.ac.uk/id/eprint/13537/

| Usage gu | idelines | | | | | |
|-------------|--|----|-----|-------|------------|----|
| Please | refer | to | the | usage | guidelines | at |
| http://sure | re.sunderland.ac.uk/policies.html or alternatively contact | | | | contact | |
| sure@sun | derland.ac.u | k. | | | | |

Title: "Masking is life": Experiences of Masking in Autistic and non-Autistic Adults Running Title: Masking is Life

Danielle Miller, Jon Rees and Amy Pearson

School of Psychology, Faculty of Health and Wellbeing, University of Sunderland, Sunderland, UK

Correspondence: Amy Pearson amy.pearson@sunderland.ac.uk School of Psychology Faculty of Health Sciences and V

Faculty of Health Sciences and Wellbeing

University of Sunderland

Helen McArdle House

City Campus

Sunderland

SR1 3SD

Tel: 0191 515 2279

Keywords: Autism, Camouflaging, Masking, Neurodiversity

Abstract word count: 238 Manuscript word count: 5389 Lay Summary word count: 419

Abstract

Background: Autistic masking is an emerging research area, and so far, research has suggested that masking has a negative effect on autistic people. Masking relates to general social practices (such as identity management) and is often driven by stigma avoidance. Many non-autistic people also experience stigma that might drive them to suppress aspects of their identity. In this study we investigate similarities and difference in experiences of masking in autistic and non-autistic people.

Method: We conducted an online survey about experiences and views of masking in autistic people (n=144), neurodivergent people without an autism diagnosis (n=49), and neurotypical people (n=45) recruited via social media. We used thematic analysis to analyse responses to open-ended items about masking, using an inductive approach, at a semantic level, with a critical realist paradigm.

Results: Thematic analysis revealed that some aspects of masking are shared across autistic and non-autistic people, such as utilising mimicry of others as a social strategy or feeling exhausted from masking. All groups reported that masking made them feel disconnected from their true sense of identity and had a negative effect on them. Other aspects of masking seemed more specific to autistic people, such as sensory suppression, and masking leading to suicidal ideation.

Conclusions: Our findings suggest that many aspects of masking are experienced across different neurotypes and are likely related to outside perceptions of difference and stigma. It

is likely that what we call 'autistic masking' is similar to other forms of stigma management previously theorised. Some aspects of masking do seem more specific to the autistic neurotype (e.g. suppression of stimming), and should be explored further in order to provide support for autistic people recovering from the negative impact of masking.

Lay Summary

Why was this study done?

Masking is the process of intentionally, or unintentionally hiding aspects of yourself in order to avoid harm. Recent research has suggested that autistic people might mask a lot, and that this can lead to long term problems in mental health. At the moment we don't know which parts of masking are specific to autistic people, and which parts might be experienced by others, especially other neurodivergent people who aren't autistic, for example people with Attention Deficit Hyperactivity Disorder (ADHD).

What was the purpose of this study?

The purpose of this study was to find out about masking in autistic and non-autistic people, to find out whether some parts of masking are specific to autistic people, or experienced by others.

What did the researchers do?

We asked conducted an online survey about masking with three groups of people: autistic people, non-autistic people who have another neurodevelopmental or mental health diagnosis - like dyslexia, ADHD or depression, and non-autistic people who don't have any neurodevelopmental or mental health diagnoses. The survey included an open text box for people to write about their experiences of masking and their opinions about masking. We analysed these responses using a method called "thematic analysis." This method helps us look for ideas that people commonly talk about in their answers

What were the results of this study?

We found out that autistic and non-autistic people think masking is very complicated and has a negative effect on them. Both autistic and non-autistic people said that masking made them exhausted and really unhappy, and that it made them feel like people didn't know the 'real them'. Only autistic people mentioned that masking sometimes makes them feel suicidal, and that masking includes things that other groups didn't mention (like trying to hide being upset by sensory things like loud noise).

What do these findings add to what was already known?

Our findings suggest that some aspects of masking don't just affect autistic people (like feeling like people don't know the real you), but other parts might be more unique to autistic people (like hiding stims from other people).

What are potential weaknesses in this study?

More women than men and non-binary people took part, which means that we know more about women than other people. We also don't really know whether everyone in the nonautistic groups were really 'not autistic'. They could be autistic people who don't have a diagnosis, which might affect our results.

How will these findings help autistic people now or in the future?

We hope our findings will help people to understand how masking affects autistic and nonautistic people. We also hope that people designing new studies will look at important things like whether someone is autistic *and* non-binary, or autistic *and* ADHD as these things might affect their experiences.

Introduction

The term 'Neurodiversity' is used to describe the idea that human brains vary across a range of domains including motor and sensory processing, executive function, and language.^{1,2} Twentieth century psychological research was grounded in the assumption that the majority of the population display 'neurotypicality', or an 'average' brain in which cognitive, motor and sensory processes function in mostly similar ways³ and develop along a similar trajectory.⁴ Neurodevelopmental differences such as autism were classified as 'disorders' that varied from the assumed norm.⁵ The recent shift towards a neurodiversity based paradigm acknowledges that differences in neurological and psychological functioning are a) more common than previously thought⁶ and b) more complex than a normative vs. pathological model suggests.^{7,8}

The assumption of a neurotypical default has led to difficulty in conceptualisation and categorisation of neurodivergence, particularly autism, as it has relied on the external presentation of associated traits (i.e. lack of eye contact) as opposed to an understanding of the internal experiences of neurodivergent people (i.e. what it *feels* like to be autistic).⁹ Additionally, the omission of internal experiences in understanding autism has until recently led to the role of masking being overlooked.¹⁰

Masking is a term used by the autistic community¹¹ to describe the suppression of aspects of self and identity in order to 'fly under the radar' or 'appear normal',¹² using conscious (i.e. mimicking facial expressions) or unconscious (i.e. unintentionally suppressing aspects of one's identity) means.¹³ We use "masking" as an umbrella term to capture experiences that

have been referred to as 'camouflaging',¹³ 'compensation'¹⁴ and 'adaptive morphing'.¹⁵ Masking is an emerging area in autism research, and our understanding is still limited.^{16,17} It is proposed as one explanation for gender disparities in autism diagnosis,¹⁰ and late diagnosis,¹⁸ and has been linked to a range of negative outcomes for autistic adults such as mental health difficulties,^{19,20} burnout,²¹ and suicidality.²²

Research so far has focused on masking as an autism-specific experience designed to 'pass' as non-autistic in social situations¹⁶ and to avoid stigma^{11,23-25} associated with negative stereotypes of autistic people.²⁶ Stigma is the attribution of a negative status to an individual on the basis of a characteristic that marks them out as 'discreditable' or 'spoiled'.²⁷ These characteristics might be 'visible' (such as gender), or 'invisible' (like autism),²⁸ and a single individual may have multiple stigmatised characteristics (i.e. being a woman *and* autistic). The experience of stigma is certainly not unique to autistic people; many marginalised (socially excluded) people (i.e. other forms of neurodiversity, minority sexual orientations)^{29,30} experience stigma, and there has been extensive research to examine both the causes and consequences in these groups.³⁰

Accordingly, though research into autistic masking is in its infancy, the social psychological literature has examined concepts similar to masking at length in relation to both stigma (i.e. concealment)³¹ and contextual identity shifting (i.e. self-monitoring and identity management)^{28,32} in people with stigmatised characteristics.³⁰ So far there has been little consideration of whether there is something specifically different about autistic masking^{16,17} in comparison to other forms of identity management and stigma avoidance used by other neurodivergent and neurotypical people, and what these differences might be. This is important to know, as it can help us to understand the role that general societal issues (i.e.

stigma) play in masking, as well as specific issues that different groups of people might face that lead to masking, and its maintained presence.

In order to address this issue, the current study aimed to develop our knowledge of masking in autistic and non-autistic (both neurodivergent and neurotypical) adults. As this is an area with very little empirical investigation, we used a qualitative approach to explore the experiences and thoughts of masking in autistic and non-autistic adults.

Method

Research Question

What are the similarities and differences between experiences labelled as 'masking' by autistic and non-autistic adults?

To address this we used one open ended prompt (Similar to Hull)¹³ as part of a larger online questionnaire study (the results of which we do not discuss in this paper).

Participants

We recruited 461 participants online using social media (Facebook and Twitter) with an advert that linked to the study, which was hosted on Qualtrics. We stated that we were looking for people over the age of 18 years to take part in a study on the link between autistic traits and masking (i.e., 'masking difficulties, such as forcing eye contact or planning a conversation'), and that participants did not have to be autistic to take part. There were no further exclusion criteria applied. There were 250 self-reported autistic adults, 130 adults

who reported no neurodevelopmental, neurological or mental health diagnoses (Neurotypical, or NT) and 81 self-reported neurodivergent (without a diagnosis of autism, ND-) adults. Of these 461 participants, 144 autistic, 45 NT and 49 ND- people provided textual data about masking. Responses ranged in length from one short sentence to multiple sentences. These participants comprise the final sample (see Table 1).

We asked participants whether they had ever received a diagnosis of autism, or any other form of neurodiversity/mental health condition. We did not specify whether people had to be clinically diagnosed, thus we cannot be sure how many people in the sample had a clinical diagnosis, and how many were self-diagnosed. In the neurodivergent group we chose to include both neurodevelopmental and neurological differences and mental health diagnoses as neurodivergence. Though there is debate around whether mental health diagnoses should be included under the label of 'neurodivergence', we have included both here as both are likely to experience marginalisation on the basis of their neurology.²⁹ The most common diagnoses in this group were depression (N=28), anxiety (N=25), dyslexia (N=6) and Attention Deficit Hyperactivity Disorder, or ADHD (N=5). In both the autistic and neurodivergent groups, many participants reported multiple (i.e. anxiety and depression, Autism and ADHD) diagnoses. Several participants in the ND- and NT groups reported that they suspected being autistic/neurodivergent in their qualitative comments. However, as these participants did not self-identify themselves as autistic and/or ND in the demographic data we decided not to place them in these groups post hoc. We discuss the impact of these groupings further in the discussion. Participation was anonymous, and no incentives were offered. This study was approved by the University of Sunderland Research Ethics committee.

XXX TABLE 1 HERE XXX

Methodological Approach

We used an inductive thematic approach to analyse the open-text data (following Braun and Clarke)³³ as it allows for a reflexive consideration of a dataset. Though there is a growing body of research on masking^{10,16} we wanted to avoid relying on previous conceptualisations (i.e. masking, assimilation, compensation) to interpret our findings where possible, to allow for new ideas to emerge. This was particularly important given that we were examining masking in people with neurotypes other than autistic, which could provide new perspectives in comparison to previous research.

We drew upon a critical realist³⁴ approach in our interpretations, recognising that the interaction between neurotype and the social world is complex and subjective, yet has material impact in the lives of our participants. Two of the authors (one diagnosed autistic, one undergoing diagnostic assessment) read and independently coded the text data. We were not concerned here with establishing reliability, but with the potential for exploring whether our differing experiences and knowledge (particularly in regard to masking) influenced how we drew meaning from the experiences of our participants, and in how we might identify different items as salient. Codes were generated using semantic coding, which we examined for shared conceptual relationships to form themes (i.e. the codes 'social hell' and 'for whose benefit' were grouped under the theme 'external influences'). Finally, we sent these codes and themes to the third author and an independent autistic expert (both autistic men), who both agreed with the final organisation.

Procedure

Participants took part by clicking a link to the study, which was hosted on Qualtrics. They read an information sheet detailing the aims of the study, with contact details for the researcher and related charitable support services. To provide consent they clicked to confirm that they were **a**) over the age of 18, **b**) had read and understood the information sheet, and **c**) consented to taking part in the study. As the data was collected as part of a larger (unpublished) project, participants were directed to a page to provide demographic information, before they proceeded to complete two questionnaires. After completing the questionnaires, participants were provided with an open text box to detail their experiences of masking ('Please use this section to write down any experiences of masking your difficulties, or any opinions of masking you may have'). Finally, we thanked participants for their time and provided a final open text box for any further comments.

Results

We identified seven themes (see Table 2). Most of the themes were shared across all three groups, however one of the themes (*4. Neurotype Nuances*) was specific to the autistic participants.

The themes reported here are not completely separate entities; there is distinct overlap and interaction between each theme discussed. Whilst we have done our best to group them, none truly sit in isolation and it is only by taking into account how they interact that we can estimate the impact of masking on the individual. For example, the experiences outlined in

themes 1-6 are situated within the developmental context of time. We have labelled each quote with the group (autistic, ND-, and NT), gender (woman, man, non-binary person), and age of the person it came from.

XXX TABLE 2 HERE XXX

External Manifestations: What others see

Participants wrote about the external manifestations of the mask, reporting the strategies that they use for the parts of the mask that are seen by observers, including mirroring behaviour, expressions, dress sense, and speech:

"I copy people's phrases, and dress sense too" (Autistic woman, 41).

"Growing up I studied facial features, behaviours, and body language to mimic more accurately" (ND – woman, 21)

"I used to copy friends and practice in front of the mirror as a child" (NT woman, 54).

These strategies were mentioned by all three groups and seem to reflect general behaviours used to fit in with conspecifics outlined in the social psychological literature, and previous literature on masking. 'Life is masking, masking is life': Internal Identity and loss

Participants reported the toll that masking takes internally, impacting on their sense of self and identity. One autistic participant gave an account of how pervasive and allencompassing masking can be, "Life is masking, masking is life" (Autistic woman, 35). This statement is indicative of the complexity of masking, and the interaction between all of the themes reported in that masking can pervade a person's entire identity, life and sense of selfhood. Masking goes far beyond what is 'seen' and is inherently tied up in the personal experience of the individual. It can deeply affect a person's identity and lead to confusion about who they 'really 'are. As one person wrote, "I have a lower sense of self than most seem to. I feel foreign to myself because all the behaviours I've adopted to mask have been to keep myself safe, but they've also boxed me into a corner and stifled me" (NT non-binary person, 23). One participant compared the prolonged experience of masking as akin to grief, "I feel that I am grieving for the little girl who just wanted her own space and peace to read and play with dolls. She was forced to be someone else. I feel as though I am wearing a different person. I don't know where I went, or who I could have become if I hadn't been forced to be someone else." (NT woman, 48). Here the interaction between identity and external pressures can be seen, in that masking can provide a protective mechanism from outside sources of harm, but leads to internal fracture and difficulty in knowing ones 'true self', leaving people truly stuck between a rock and a hard place.

'A huge emotional and physical toll'': Masking as a resource drain

Both autistic and non-autistic participants wrote of the exhaustion and burnout that masking can bring, impacting on physical and mental health. For example, one autistic participant

wrote, "I can manage to exist in an NT world as long as I'm ok mentally, if I'm stressed...it all turns to jelly, as do I" (Autistic man, 57) and a non-autistic participant wrote, "almost spinning like a top mentally...it can take a day or two to recover" (ND- woman, 42). Autistic participants also reported that masking can lead to increased suicidality, "I didn't learn that I only get suicidal during meltdowns until I removed all masking obligations...I spent 13 years burnt out" (Autistic non-binary person, 34). However this was not reported in the ND- and no-diagnosis groups. Autistic participants also specifically mentioned 'dangerous' coping mechanisms. One wrote about restricted eating "In order to try and fit in somewhere... I have suffered with Anorexia Nervosa for 8 years" (Autistic woman, 29). Another wrote about substance use "I used to use alcohol to do it, but recently I gave it up so masking has become more difficult" (Autistic woman, 24). These comments support the idea that there may be something specific to the experience of masking in autistic people that might make it particularly harmful, however this needs further investigation.

Neurotype Nuances

Autistic participants specifically mentioned the interaction between cognitive and sensory processing, and masking. Some wrote about suppressing responses to sensory discomfort: "*I frequently mask sensory differences such as pain due to sounds with too high pitch, too low pitch, or too high volume*" (Autistic woman, 22). Others wrote about sensory processing difficulties making masking harder: "*Sensory processing difficulties, particularly auditory, make masking tougher*" (Autistic non-binary person, 25). Several people wrote about suppressing their stims, for example:

"many of us hide stimming by choosing discreet stims" (Autistic woman, 22)

"the worst part is not being able to stim when I need to" (Autistic woman, 49).

In addition, one participant talked about their use of memory as a social tool for masking, "*I* remember lots of details about people so I have things that I know they want to talk about" (Autistic woman, 39). The non-autistic participants did not mention any similar experiences. These comments are indicative of individual facets to masking that might relate specifically to the experience of one's own neurotype.

"No one believes me": External Consequences

Participants in all groups wrote about the negative external consequences that come with masking. In addition to feeling a disconnect with their inner self, some mentioned how hiding one's true self can prevent a real connection forming with others: *"The only person in the world that even begins to know the real me is my husband"* (Autistic woman, 49). Others wrote about the confusion of others when they started to remove the mask: *"some people who were friends before are puzzled by this different me...it's scary for me"* (Autistic man, 48). Moreover, others wrote of how this led to being invalidated by those around them:

"masking...contributes to the disbelief of others" (ND- woman, 32)

"I have struggles to be myself...yet doctors claim there is nothing wrong with me" (NT woman, 22)

"my ex told me that I was faking being autistic" (Autistic non-binary, 21)

"I have chronic pain...It's a new normal for me, however it also makes it difficult to talk about because people the look at me and say "I know but you look fine" (ND-woman, 31).

Despite the consequences of masking, these experiences of masking are not universal, and others saw consequence in *not* masking: "*I have never been able to mask, which is why I have always been a target for bullying and abuse*" (Autistic woman, 36). Other participants wrote about the complexity of their feelings about masking: "*If I'd have been diagnosed early, I feel like I never would have needed to develop most of the skills I use to survive*" (ND- man, 33). These statements display the dual nature of masking: whilst some people acknowledge that masking has enabled them to partially cope in a world that does not feel designed for them, it has a heavy impact on the inner self. For those who report being unable to mask, they feel this has impacted on their acceptance by others and led to victimisation. These comments suggest that regardless of the coping strategy attempted there is no optimal outcome in which the person is unharmed (either by the exhaustion of maintaining a mask, or the resulting social consequences of not masking). The explanation for this is simple: the problem lies with the external world, and not with the person themselves.

"Masking is the language of NT's": External Influences

Some participants believed that others find masking natural, which is consistent with aspects of identity shifting as a social affiliation strategy. As one participant astutely noted, "*Masking is the language of NTS, it's not a direct language but an automatic one that autistics have to*

learn, it takes years and even then there is no perfection to it." (Autistic woman, 41). Here the difficulty with using non-native social communication styles to promote social cohesion is emphasised. There is currently very little known about the general native social affiliation strategies used by autistic people.

The role of external influences in masking also link back into consequences, and avoiding victimisation. One participant reflected "I grew up believing that my love for science, nature, and mechanics was for nerds and I learned that nerd were harassedSo I learned to study, analyse and mimic the popular kids. Like I was preparing to survive something intense: social interactions." (ND- man, 32). Here we can see the role that stigma plays in masking, learning to avoid harassment and dehumanisation becoming a key factor in learning to 'blend in' where possible.

Time

Time was an important factor in the development of masking, with many participants emphasising learning as a young child to suppress aspects of themselves. As one participant recounted: "*I have used masking from a very young age because I thought I was broken*" (Autistic non-binary person, 18). Participants also wrote about how over time masking became instinctual and how it became difficult to work out where they ended and the mask begun, to 'unlearn' the mask: "*I think I am very good at masking, so good I'm struggling to tell what's mask and what's not*" (ND- man, 33).

Some participants also wrote about masking being unconscious, being unaware that they were 'masking', but knowing that they had to hide parts of themselves "*I have spent my life masking without knowing I was doing it*" (ND- woman, 47). One comment stood out in

particular, emphasising that the ability to talk about masking is inherently connected to being able to realise that you are even doing it:

"It's very hard to pick apart what you have been masking as you don't know what's normal...you begin unravelling all the examples throughout your life, it takes a huge emotional and physical toll. I find it confusing how I have coped before and now I cannot" (ND- Woman, 36).

One NT participant reflected on how taking part in the study had made her reflect on her difficulties: "*I have just cried through the questions realising how hard things have been for me*" (NT Woman, 36). Without a reference point many people assume that the difficulties they experience are either universal, or that there is something 'wrong' with them for finding things that everyone else appears to do effortlessly, so hard. This was reflected in the comments of one autistic participant, who wrote "*It was only through talking to my therapist about masking that I realised I'd been doing it my entire life. I just assumed that social situations were mentally taxing for everyone and that everyone was exhausted*" (Autistic man, 36). Other participants discussed how masking had gotten more difficult with age:

"It has become harder to mask as I have gotten older and the menopause has ramped up the anxiety no end" (NT woman, 50)

"Masking has become more difficult to continue over the years, so now I don't do it as much" (Autistic woman, 35).

These comments suggest that being more 'practiced' at masking does not lessen its impact on the individual doing it, and emphasise the importance of more research into masking across the lifespan.

Discussion

The current study sought to examine experiences of masking in autistic and non-autistic adults using a qualitative approach. Thematic analysis revealed that experiences of masking across groups were related to a set of complex, interlinked factors. Whilst empirical research so far has built up our knowledge of strategies (i.e. external indicators, the concept of 'compensation'),^{13,14,35,36} masking across contexts¹⁹ and identifying the consequences of masking,^{19,37} there has been less of a focus on the interaction between the different components and whether these are specific to autistic people. The overlap in masking experiences across the groups supports the view that some aspects of masking are likely to be similar to constructs outlined in the literature on stigma³⁰ and not limited to autistic people. However, the autistic participants did raise some specific issues not mentioned by the other groups. Here we provide further discussion of these findings.

All groups reported using external indicators such as clothing choice, vocal expressions and tone, and facial expression to fit in, which is consistent with previous research into masking.¹³ These techniques are arguably not limited to autistic people and relate to basic social affiliation strategies³⁸ used by humans to signal interests to, and align with, likeminded others.³⁸ Participants in this study referred to external (social) influence as the main driving factor in masking, including self-protection, fear of repercussion, and negative consequences, which is consistent with previous research.^{19,39} Social identity theory³⁸ provides a framework

for understanding how aspects of our identity may fluctuate in different contexts in order to 'fit in'. These strategies have traditionally been described in terms of signalling likemindedness and expressing different aspects of identity⁴⁰ rather than identity suppression. However when these external social indicators are based upon non-native social strategies (sometimes referred to as 'compensation')³⁶ they can lead to internal disjunction, exhaustion, and a wider loss of selfhood. It is not the strategy itself that is the issue, but that it is not a reflection of the participants true identity or native social communication style. There is currently very little known about the native social affiliation methods used by autistic and other neurodivergent people and how these may differ to neurotypical people.³⁹ If we are to understand masking, it is important that we develop a good understanding of social identity across neurotypes.

This loss of identity and the experience of grief was a common experience across participants, who described the impact of feeling like they didn't know their true selves, or wondered who they could have been if they hadn't felt the need to mask. This is consistent with previous research which shows that a disconnection with one's identity has a negative effect across those who feel like they cannot be themselves,^{19,25} and is often driven by outside pressures and stigma.^{19,41} Masking has been associated with mental health issues in autistic people^{19,20} which is unsurprising given the negative impact it has upon their sense of self. Our findings support previous research suggesting that masking (as a facet of stigma avoidance) has both physical and mental consequences across marginalised groups^{30,41}. More research is needed to address the relationship between masking and mental health across neurotypes. An additional consequence of masking was the stress that came from participants feeling like other people did not know the 'real them', and that their relationships were on based upon people knowing them as they really are. Research has suggested that a feeling of community

belongingness not only provides a sense of kinship, but can also mitigate the effects of internalised stigma.^{30,31}

Conversely, others spoke of how being unable to mask led to being victimised for appearing outwardly different, however research has also suggested that masking may be related to victimisation.⁴² These kinds of situations can be referred to as a 'double-bind' in which a person has negative experiences regardless of which actions they try to take.²⁴ Several participants across groups also spoke about how masking could lead to invalidation of their identity and minimise some of their personal challenges. This is an important aspect of masking and again raises the question of who masking benefits? Previous research into the costs of masking¹⁹ suggests that the cost to the individual is doubly high as they are putting effort into sustaining social cohesion with those who do not put the same effort in to understanding them in return.⁴³ These comments are indicative of the difficulty that many people are faced with in trying to navigate social situations and avoid negative responses from others. It also reinforces that this difficulty is not limited to autistic people, but is an experience of those who do not 'fit in' and are stigmatised because of it. Whilst reducing stigma and dehumanising attitudes towards those that are different is a rather long term and gargantuan undertaking, more research into the experience of stigma across neurotypes and what can be done to mitigate its impact in the meantime can help to improve the lives of those who are stigmatised.^{24,41}

All of the groups spoke of how draining masking is, which is consistent with previous research^{19,30} but the autistic participants alone related this exhaustion to suicidality³⁷ and unhealthy coping mechanisms. This may be related to removal or suppression of usual healthy coping mechanisms such as stimming (mentioned in theme 4), as coping strategies are an important buffer against the effects of stigma.³⁰ This may also help to explain the link

between masking and negative outcomes like burnout.²¹ The removal of coping mechanisms in the face of long term suppression of distress may lead to difficulty in identifying interoceptive cues, impacting on the ability to manage environmental stress,¹⁷ and intensify mental health difficulties.⁴⁴ Though interoceptive difficulties are prevalent in autistic people,⁴⁴ they are seen in other populations, including people with Post Traumatic Stress Disorder (PTSD)⁴⁵ and ADHD.⁴⁶ Further research should aim to establish whether the burnout that autistic and other neurodivergent populations experience is distinct from a) each other, and b) from burnout characterised in the medical literature, as well as the preceding contributing factors such as stigma and stigma management.

The participants emphasised the role that time plays in masking and how their masking often began in childhood. These findings stress the needs for more developmental research into when masking begins, what causes it, and what we can do to support people. Recent research has started to investigate masking in adolescents.^{47,48} Bernardin and colleagues⁴⁸ found that both autistic and non-autistic young people mask for similar reasons to adults (i.e. to fit in, to avoid negative social judgements), and that masking leads to exhaustion in autistic young people in particular. Hull and colleagues⁴⁹ found a relationship between executive functioning and self-reported masking in adolescents, in that those with higher scores on a self-reported masking questionnaire also had higher scores on an executive functioning task. It is likely that masking is only possible so long as the person masking has sufficient cognitive resource to do so, and that masking itself is incredibly draining in the long term making it difficult to sustain for a prolonged period without significant negative impact on the individual (i.e. the burnout and exhaustion that participants in the current study report).

Autistic participants alone referred to the interaction between masking and aspects of their neurotype. Specifically they referred to the use of memory as a tool to promote success in cross neurotype interactions, which is consistent with previous research,³⁶ and the impact of sensory processing differences (i.e. suppressing sensory responses).⁴⁴ This aligns with the idea that some aspects of masking might be more specific to autistic people (i.e. suppressing sensory distress, though arguably this is likely to be applicable to other populations such as people with Sensory Processing Disorder), whereas others are more universal to marginalised people (such as hiding parts of your identity to avoid stigma) in general. However it is important to recognise that many of our autistic (and ND-) participants had multiple diagnoses. Experiences of multiple co-occurring forms of neurodiversity and physical disability appear to be common,⁵⁰ thus we suggest that research such as ours is not used to try and stratify aspects of masking on the basis of neurotype. Instead it can help us to develop knowledge about specific issues people might face that interact with their neurotype and how we can support them, in addition to how people who are marginalised across multiple axes may develop the means to survive in a society which stigmatises them. Though we had a lack of demographic data relating to other aspects of identity (i.e. sexual orientation, race/ethnicity), these are important factors that should be explored in relation to how they intersect with neurotype specific stigmas. Identity cannot be isolated into singular, neat facets and research to address masking and stigma should take this into account.

Limitations

One major limitation is the self-selecting nature of online research. The participants who gave the most detailed accounts of masking are the ones for whom it has had the greatest impact, and whom are aware of their own masking. This makes it difficult to account for people who a) mask but are not aware that they are masking, b) may use alternative terms to describe their masking or are unfamiliar with the terms used in the current study, or c) do not mask, and thus have nothing to say because it has little bearing on their lives. It is important that we try to involve a wider community of people in research so that a range of experiences are represented to inform our understanding, e.g. what are the experiences of masking in nonspeaking autistic people, or people with high support needs. We did not ask about communication preferences or support needs in the current study, so we cannot make any assumptions about how representative our findings are to the wider autistic population. Our findings also raised the issue of how we can truly group people by neurotype in such studies. Participants self-reported their diagnostic status, yet there were several participants in the NT group whose experiences appeared to align with autistic and ND participants, and who expressed doubt at their NT status. This issue has wider implications for any work which attempts to make comparisons centered around neurotype, where we assume that people who do not have a diagnosis are 'neurotypical' (and rely on their self-report). Often, there are questions around online research as to how we can confirm the neurodivergent status of our participants (i.e. do we include screening measures alongside self-report), however there is little focus on this issue in the opposite direction, how we confirm that a participant truly is 'neurotypical'. We do not have a solution to this problem, but think it worthy of acknowledgement.

Our sample was majority female, which is not representative of the wider population of autistic and non-autistic people. Additionally, we did not collect any further demographic data (i.e. race/ethnicity, nationality) besides age, gender, and diagnoses which limits our ability to generalise the findings of this research, and to understand the relationship between masking and other aspects of identity. To understand the nuance of the relationship between

autistic masking and identity, we need to take an intersectional approach.⁵¹ Identity is made up of a range of factors (i.e. gender)³⁰ that might also contribute towards how society views us and our experiences of stigmatisation. Thus, an autistic person engaging in masking will not be simply 'covering up' their autistic behaviours, but also monitoring other aspects of self and identity. Currently it is unclear how specific aspects of autistic masking (i.e. forcing eye contact) relate to other forms of social masking and stigma management (i.e. not talking about certain topics in the presence of people who may not be interested, which is arguably not limited to autistic people). Though our study provides some initial insight into this issue, we need to conduct more research into this area taking into account intersectional identities⁵¹ (i.e. sexuality, gender, race/ethnicity) in order gain a deeper understanding. Further demographic data, and a more representative sample can help us to understand how different aspects of identity intersect in experiences of masking. We cannot isolate 'autistic' identity from other aspects of a person's identity and assess masking as thus. Much more research in this area is needed.

Future Directions

At the time that this data was collected, empirical study into masking was incredibly sparse. Over the last couple of years this area has grown, though there is still much to be explored. Two key questions that it is essential to address going forward is *why* and *how* the aspects of masking that are specific and harmful to autistic people develop. Our participants spoke of the developmental impact of identity suppression and the trauma that this has caused. Whilst recognising and understanding the strategies that people might use can help us to inform clinicians about factors that could potentially affect diagnosis, providing support for those harmed by masking means unpicking the underlying trauma and stigma experiences that led to the development of that mask. We suggest that future research strongly focus on

intersectionality, the developmental aspects of masking, and the relationship between masking and trauma in both autistic *and* non-autistic people. We also suggest that a focus on stigma and the associated theory³⁰ is essential for framing why masking in autistic and other neurodivergent people occurs.

Conclusion

The current study examined experiences of masking across different neurotypes, including both autistic and non-autistic adults. We found that masking is not limited to autistic people, which is consistent with theory on identity and stigma management, However, some aspects of masking appear to be specific to the autistic experience (i.e., suppressing stims). Data also built up a picture of masking as a multidimensional, interactive concept that develops across the lifespan and is driven by stigma. Future research should examine masking in relation to intersectional aspects of identity, in both autistic and non-autistic people.

Acknowledgements

The authors would like to thank Kieran Rose for his insightful and constructive discussion in the interpretation of these results and writing of this manuscript. We would also like to thank everyone who gave their time to participate in this study, for sharing such personal experiences with us.

Authorship Confirmation Statement

DM and AP contributed to the design, data collection, data analysis and writing of the manuscript. JR contributed to the analysis, writing and editing of the manuscript. All authors have reviewed and approved this manuscript.

Author Disclosure Statement

None of the authors have competing financial conflicts of interest.

Funding Information

This study was not funded.

References

- den Houting J. Neurodiversity: An insider's perspective. *Autism*. Published online 2019. doi:10.1177/1362361318820762
- Baron-Cohen S. Editorial Perspective: Neurodiversity a revolutionary concept for autism and psychiatry. *J Child Psychol Psychiatry Allied Discip*. 2017; 58:744-747. doi:10.1111/jcpp.12703
- Filippi R, Karmiloff-Smith A. What can neurodevelopmental disorders teach us about typical development? In: *Current Issues in Developmental Disorders*. London Psychology Press; 2013; 193-209 doi:10.4324/9780203100288
- Thomas MSC, Annaz D, Ansari D, Scerif G, Jarrold C, Karmiloff-Smith A. Using developmental trajectories to understand developmental disorders. *J Speech, Lang Hear Res.* 2009; 52(2):336-358. doi:10.1044/1092-4388(2009/07-0144)
- Karmiloff-Smith A, Thomas MSC. Developmental disorders. In: Arbib, M.A. (ed). The Handbook of Brain Theory and Neural Networks (2nd Edition). Cambridge, U.S. MIT Press. 2002:339-342.
- Happé F, Frith U. Annual Research Review: Looking back to look forward–changes in the concept of autism and implications for future research. *J Child Psychol Psychiatry*. 2020; 61(3):218-232.
- Chapman R. Defining neurodiversity for research and practice. *Neurodiversity Stud A New Crit Paradig.* In: *Neurodiversity Studies: A New Critical Paradigm.* Routledge. 2020:14.

- Singer J. Why can't you be normal for once in your life? From a 'Problem with no Name'to a new category of disability. *Disabil discourse*. Published online 1999:59-67.
- 9. Milton D. A Mismatch of Salience: Explorations of the Nature of Autism from Theory to Practice. Pavilion Press; 2017. https://www.pavpub.com/a-mismatch-of-salience/
- Hull L, Petrides K V., Mandy W. The Female Autism Phenotype and Camouflaging: a Narrative Review. *Rev J Autism Dev Disord*. Published online Jan 29th 2020. doi:10.1007/s40489-020-00197-9
- 11. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disabil Soc.* 2016;31(4):520-534.
- 12. Willey LH. Pretending to Be Normal: Living with Asperger's Syndrome (Autism Spectrum Disorder) Expanded Edition. London. Jessica Kingsley Publishers; 2014.
- Hull L, Petrides K V., Allison C, et al. "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *J Autism Dev Disord*. 2017; 47:2519-2534. doi:10.1007/s10803-017-3166-5
- Livingston LA, Happé F. Conceptualising compensation in neurodevelopmental disorders: Reflections from autism spectrum disorder. *Neurosci Biobehav Rev.* 2017; 80:729-742. doi:10.1016/j.neubiorev.2017.06.005
- Lawson WB. Adaptive Morphing and Coping with Social Threat in Autism: An Autistic Perspective. J Intellect Disabil Treat. 2020;8:519-526.
- Lai M-C, Hull L, Mandy W, et al. Commentary: 'Camouflaging' in autistic people reflection on Fombonne (2020). *J Child Psychol Psychiatry*. 2020;n/a(n/a). doi:https://doi.org/10.1111/jcpp.13344
- Pearson A, Rose K. A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism in Adulthood*. Published online 2020. doi:10.31219/osf.io/6rwa5

- Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. J Autism Dev Disord. 2016; 46:3281-3294. doi:10.1007/s10803-016-2872-8
- Cage E, Troxell-Whitman Z. Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults. *J Autism Dev Disord*. 2019; 49:1899-1911. doi:10.1007/s10803-018-03878-x
- Hull L, Levy L, Lai M-C, et al. Is social camouflaging associated with anxiety and depression in autistic adults? *Mol Autism*. 2021; 12(1):13. doi:10.1186/s13229-021-00421-1
- Raymaker DM, Teo AR, Steckler NA, et al. "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": defining autistic burnout. *Autism in Adulthood*. 2020;2:2:132-143. doi:10.1089/aut.2019.0079
- 22. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism.* 2018; 9(42) doi:10.1186/s13229-018-0226-4
- Cage E, Di Monaco J, Newell V. Understanding, attitudes and dehumanisation towards autistic people. *Autism.* 2019; 23(6):1373-1383.
- 24. Botha M, Dibb B, Frost DM. "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disability and Society*. Published online 6th October 2020
- 25. Milton D, Moon L. The normalisation agenda and the psycho-emotional disablement of autistic people. *Auton Crit J Interdiscip Autism Stud.* 2012;1(1).
- 26. Wood C, Freeth M. Students' Stereotypes of Autism. *J Educ Issues*. 2016;2(2):131-140.
- 27. Goffman E. Stigma: Notes on the Management of Spoiled Identity. Penguin Books;1963.

- 28. Goffman E. *The Presentation of Self in Everyday Life. 1959.* Vol 259. Garden City;
 2002.
- McWade B, Milton D, Beresford P. Mad studies and neurodiversity: a dialogue. Disabil Soc. 2015;30(2):305-309. doi:10.1080/09687599.2014.1000512
- 30. Frost DM. Social stigma and its consequences for the socially stigmatized. *Soc Personal Psychol Compass*. 2011;5(11):824-839.
- 31. Botha M. Autistic community connectedness as a buffer against the effects of minority stress. [Doctoral Thesis]. Surrey,UK. University of Surrey. Published online 2020. http://epubs.surrey.ac.uk/854098/7/Autistic Community Connectedness as a Buffer Against Minority Stress - M Botha.pdf
- Snyder M. Public Appearances, Private Realities: The Psychology of Self-Monitoring.
 WH Freeman/Times Books/Henry Holt & Co; 1987.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;
 3(2):77-101. doi:10.1191/1478088706qp063oa
- Bhaskar R. *Reclaiming Reality: A Critical Introduction to Contemporary Philosophy*.Taylor & Francis; 2010.
- Hull L, Mandy W, Lai MC, et al. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *J Autism Dev Disord*. 2019; 49:819-833. doi:10.1007/s10803-018-3792-6
- Livingston LA, Shah P, Milner V, Happé F. Quantifying compensatory strategies in adults with and without diagnosed autism. *Mol Autism*. 2020; 11(15). doi:10.1186/s13229-019-0308-y
- Cassidy SA, Gould K, Townsend E, Pelton M, Robertson AE, Rodgers J. Is
 Camouflaging Autistic Traits Associated with Suicidal Thoughts and Behaviours?
 Expanding the Interpersonal Psychological Theory of Suicide in an Undergraduate

Student Sample. *J Autism Dev Disord*. 2019; 50:3638-3648. doi:10.1007/s10803-019-04323-3

- Tajfel H, Turner JC, Austin WG, Worchel S. An integrative theory of intergroup conflict. Organ identity A Read. 1979; 56:65.
- Cook J, Crane L, Bourne L, Hull L, Mandy W. Camouflaging in an everyday social context: An interpersonal recall study. *Autism.* Published online February 19, 2021:1362361321992641. doi:10.1177/1362361321992641
- Hogg MA, Terry DJ, White KM. A tale of two theories: A critical comparison of identity theory with social identity theory. *Soc Psychol Q*. Published online 1995:255-269.
- 41. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: A Social Identity Theory approach. *J Autism Dev Disord*.
 Published online 2021:1-11.
- 42. Forster S, Pearson A. "Bullies tend to be obvious": autistic adults perceptions of friendship and the concept of 'mate crime'. *Disabil Soc*. Published online 2020. doi:10.1080/09687599.2019.1680347
- Milton DEM. On the ontological status of autism: the 'double empathy problem.' *Disabil Soc.* 2012;27(6):883-887.
- 44. Fulton R, Reardon E, Kate R, Jones R. Sensory Trauma: Autism, Sensory Difference and the Daily Experience of Fear. 1st ed. Autism Wellbeing CIC; 2020.
- 45. Van der Kolk BA. The body keeps the score: Memory and the evolving psychobiology of posttraumatic stress. *Harv Rev Psychiatry*. 1994; 1(5):253-265.
- Kutscheidt K, Dresler T, Hudak J, et al. Interoceptive awareness in patients with attention-deficit/hyperactivity disorder (ADHD). *ADHD Atten Deficit Hyperact Disord*. 2019;11(4):395-401.

- Wood-Downie H, Wong B, Kovshoff H, Mandy W, Hull L, Hadwin JA. Sex/gender differences in camouflaging in children and adolescents with autism. *J Autism Dev Disord*. Published online 2020:1-12.
- Bernardin CJ, Mason E, Lewis T, Kanne S. "You Must Become a Chameleon to Survive": Adolescent Experiences of Camouflaging. *J Autism Dev Disord*. Published online 2021:1-14.
- 49. Hull L, Petrides K V, Mandy W. Cognitive Predictors of Self-Reported Camouflaging in Autistic Adolescents. *Autism Res.* Published online 2020.
- 50. Fortuna RJ, Robinson L, Smith TH, et al. Health conditions and functional status in adults with autism: a cross-sectional evaluation. *J Gen Intern Med.* 2016;31(1):77-84.
- 51. Crenshaw KW. On Intersectionality: Essential Writings. The New Press; 2017.

| | Autistic (n = 144) | Neurodivergent (n = 49) | Neurotypical (n = 45) | |
|--------|--------------------|-------------------------|-----------------------|--|
| Age | 36.3±10.9 | 33.9±11.3 | 37.3±13.5 | |
| | (18-74) | (18-69) | (18-70) | |
| Gender | 101 Female | 42 Female | 38 Female | |
| | 28 Male | 4 Male | 3 Male | |
| | 15 Non-Binary | 3 Non-Binary | 4 Non-Binary | |

Table 1: Participant demographics recorded as mean \pm S.D (range).

| Themes | Example Codes | |
|--|---|--|
| | 1. Verbal/non-verbal strategies, | |
| 1. External Manifestations: What is seen by others | clothing, interests. | |
| 2. "Life is masking, masking is life": Internal | 2. All encompassing, loss of self. Who | |
| Identity | am I? | |
| 3. "A huge emotional and physical toll": Masking | 3. Burnout, conscious/unconscious | |
| as a resource drain | effort, resource drain, unnatural. | |
| 4. Neurotype Nuances (Autistic group only) | 4. Hiding sensory issues, memory use | |
| 5. "No one believes me": External Consequences | for masking. | |
| 6. "Masking is the language of NT's": External | 5. Prevents real connection, for whose | |
| Influences | benefit, can't win. | |
| 7. Time | 6. Self-protection, fear of | |
| | repercussions, consequences. | |
| | 7. Harder with age, practice, long tern | |

Table 2: Themes and example codes