Brief report: Does autistic community connectedness moderate the relationship between masking and wellbeing?

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Abstract

Background: Masking or camouflaging involves blending in or covering a stigmatised identity, to avoid discrimination and ‘pass’ within society. Autistic people often report masking, both intentionally and unintentionally, to get by in social situations. Autistic people who report high rates of masking also tend to experience poorer mental health. It is important we understand whether there are variables which can protect against the negative effects of masking. One such potential variable is autistic community connectedness – being part of and belonging to the autistic community. Past research suggests autistic people benefit from being socially connected to other autistic people. We investigated whether autistic community connectedness could moderate the relationship between masking and wellbeing.

Methods: One hundred and ninety-six autistic people completed an online survey including measures of autistic community connectedness, camouflaging autistic traits and mental wellbeing. We used moderation regression analysis to test whether autistic community connectedness acted as a buffer between masking and wellbeing.

Results: Higher self-reported masking related to poorer mental wellbeing. Higher autistic community connectedness related to more positive wellbeing. Higher autistic community connectedness correlated with more masking. However, there was no interaction effect, and autistic community connectedness did not moderate the relationship between masking and wellbeing.

Conclusions: Although autistic community connectedness did relate to more positive mental wellbeing overall, it did not moderate the negative relationship between masking and wellbeing. If masking relates to the prejudice faced by autistic people, those with greater attachment to the autistic community may also be more aware of discrimination against their community. Further, autistic people who are more connected might experience a higher salience of masking when moving between autistic and non-autistic settings. Tackling prejudice towards autistic people is critical in helping to protect autistic people against masking, and we must endeavour to change perceptions and increase inclusion of autistic people.

Community brief

Why is this an important issue?

Lots of autistic people say that they often have to ‘mask’ or ‘camouflage’ the fact they are autistic. This means they might (on purpose or by accident) use strategies like planning a social script before meeting someone, trying to hide their stims, or forcing themselves to use eye contact because non-autistic people expect this. Previous research has shown that the more someone masks, the more they experience poor mental health and wellbeing. We wondered whether being connected to the autistic community (“autistic community connectedness”) could help protect autistic people from these negative masking outcomes, because many autistic people talk about how they get joy out of being part of this community.

What was the purpose of this study?

We aimed to see whether autistic community connectedness could play a role in protecting autistic people against the negative effects of masking on mental wellbeing.

What did the researchers do?

We used an online survey which included questions about masking, connectedness to the autistic community, and mental wellbeing. One hundred and ninety-six autistic people completed the survey. We used an analysis called ‘moderation analysis’ which can be used to see if something is acting like a buffer or protector between two things (in this case, masking and wellbeing).

What were the results of the study?

Although people with higher autistic community connectedness generally had more positive mental wellbeing overall, we found that community connectedness was not acting like a protector. In other words, masking still related to poorer wellbeing, even when someone had high autistic community connectedness.

What do these findings add to what was already known?

Our findings show that autistic community connectedness can be something positive for mental wellbeing, but we think that masking keeps happening because there is so much stigma and prejudice towards autistic people. It’s difficult for autistic people to take the mask off, and people who are more connected to the autistic community may be even *more* aware of the prejudice and discrimination experienced by the autistic community. Our findings provide further support for the idea that masking has a lot to do with experiences of stigma.

What are potential weaknesses in the study?

Our participants were mostly female, and we recruited them via online communities. There may already be high feelings of autistic community connectedness in these participants, so our findings won’t be the same for everyone, and it would be good to have more people who actively reject being part of the autistic community within studies like ours.

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

We show that autistic community connectedness is related to wellbeing, and we need to support autistic people to feel like they can freely explore this community and decide whether

they want to get involved or not. If we want to help autistic people mask less, we really need to work harder on creating societies that are open to autistic people being authentically autistic.

Pre-print

Background

‘Masking’ or ‘camouflaging’ is an experience frequently reported for many autistic people within multiple different contexts.^{1–4} Masking involves blending in with the neurotypical majority, using intentional or unintentional ways to get by in social situations – such as developing social scripts for conversations, suppressing stimming, or forcing oneself to make eye contact.^{5,6} Due to ongoing discussions about the conceptualisation of ‘masking’,^{6,7} we mostly use the term masking in this paper, to respect the term which the autistic community tends to use most often.⁴

While many people, including autistic people, will try to maintain a positive reputation,⁸ masking goes beyond everyday reputation management as it involves the concealment of a stigmatised identity, and presenting the self as though one does not have that identity. Although there may be unique aspects of autistic masking,⁶ similar experiences have been reported for a range of other people with different stigmatised identities or experiences, for example, people who stutter,⁹ people with social anxiety,^{10–12} chronic pain,¹³ chronic illness,^{14,15} and sexual and gender minorities.^{16,17} Masking thus may persist due to the stigmatisation of autistic people, and due to the prejudice they experience in wider society.¹⁸ This masking of a stigmatised identity has a detrimental effect on wellbeing - for example, a recent systematic review highlighted that across the autism literature, masking relates to poorer mental health.³ Specifically, studies have found that higher rates of masking relate to greater depression,^{5,19,20} anxiety,^{2,20} social anxiety,²⁰ suicidality,²¹ and more broadly psychological distress²² and poorer mental wellbeing.⁵ Given these findings, it is important we try to understand if there are ways of protecting against the negative relationship between masking and wellbeing.

One potential variable that could play a protective role is autistic community connectedness (ACC). We can think of ACC in terms of having a sense of belonging and shared experiences with the autistic community, being socially connected to other autistic people, and advocating for this community (political connectedness).²³ Previous work has described how autistic people can build invisible infrastructures of support for each other in an otherwise quite hostile society, confounding the notion of autism as a strictly social, communicational deficit.²⁴ Autistic communities exist in many forms, where autistic sociality can flourish.^{24,25} Furthermore, greater ACC may act as buffer between minority stress and mental health, ameliorating against the additional stress associated with having a stigmatised minority identity.²⁶ Other research has looked at related concepts, such as autistic identity, whereby someone feels strongly that being autistic is part of who they are (their personal identity) or they identify as being similar to other autistic people (their social identity). Having a strong sense of autistic personal and/or social identity has been related to more positive wellbeing and self-esteem.^{27–29} Other studies also show how autistic people derive joy from friendships with other autistic people³⁰ and experience good rapport together.³¹ Given these potential benefits of the autistic community for wellbeing, it is worth investigating whether ACC can buffer against the negative impacts of masking. This study therefore aimed to examine whether ACC moderated the relationship between masking and mental wellbeing.

Methods

Participants

In total, 196 autistic people took part in the study. The mean age was 32.47 ($SD= 11.15$, range 18-67). Participants could write their gender identity in an open textbox - most identified as female (63.3%, $n = 124$), 28 identified as non-binary (14.3%), 25 male (12.8%), six preferred not to disclose (3%), four genderfluid (2%), four trans male (2%), three agender (1.5%), one gender non-conforming (.5%) and one demifemale (.5%). Most self-reported a formal autism diagnosis ($n = 129$, 65.8%), with 35 currently seeking a diagnosis (17.9%), 27 self-identifying but not seeking a diagnosis (13.8%), and five preferred not to say (2.6%). All participants scored above 14 on the Ritvo Autism and Aspergers Diagnostic Scale (RAADS-14; ³² mean = 32.71, $SD=6.17$, range 14–42). Most preferred identity-first language ($n = 136$, 69.4%), or had no preference ($n = 46$, 23.5%), with a minority preferring person-first language ($n = 14$, 7.1%). We present other demographic information in Table 1, with most participants White, from the UK, in employment and educated to degree level. We recruited participants via adverts on Facebook, Twitter, and Instagram, and via autism organisations, community groups and charities. Recruitment took place in June 2021.

We obtained ethical approval from the University of Stirling General University Ethics Panel Delegated Authority and all participants gave informed consent before starting the study.

[Insert Table 1 here]

Materials & Procedure

Participants completed an online survey, presented using the survey software ‘Qualtrics’. The survey took 12 minutes to complete on average, and participants first answered demographic questions (e.g., age, gender) and then the following measures:

Ritvo Autism and Asperger Diagnostic Scale (RAADS-14). ³² We used this measure as a brief screen to confirm self-reported autism diagnosis or identification among participants. Participants rated 14 statements on a 4-point scale (0 ‘never true’ to 3 ‘true now and when I was young’), related to different autistic characteristics, such as social communication, focused interests, and sensory sensitivities. A score of 14 or above suggests an autism diagnosis may be likely, with a total possible score ranging between 0 and 42. Internal consistency was acceptable (Cronbach’s $\alpha=.66$).

Autistic Community Connectedness (ACC). ²⁶ We used this measure to measure how connected to the autistic community each participant felt. Participants read ten statements and rated their agreement on a 6-point Likert scale (1, ‘strongly disagree’ to 6, ‘strongly agree’), for example, “I feel a sense of belonging to the autistic community”. Total scores could range from 10 to 60, with higher scores reflecting greater autistic community connectedness. Internal consistency was very good ($\alpha=.91$).

Camouflaging Autistic Traits Questionnaire (CATQ). ⁵ We used this measure to establish how much participants reported with using camouflaging behaviours. Participants rated 25 items on a 7-point Likert scale (1, ‘strongly disagree’ to 7, ‘strongly agree’), such as “I have developed a script to follow in social situations”. Total scores could range from 25 to 175, with higher scores indicating more camouflaging. Internal consistency was very good ($\alpha=.88$).

Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). ³³ We used the WEMWBS to measure current mental wellbeing. There are 14 items and all items in the scale are positively

worded (e.g., “I’ve been feeling cheerful”), with participants responding on a 5-point Likert scale (1, ‘none of the time’ to 5, ‘all of the time’). Total scores could range from 14 to 70, with higher scores indicating more positive wellbeing. Internal consistency was excellent ($\alpha = .92$).

Design and data analysis

This study had a cross-sectional survey design, and we analysed the data using SPSS (Version 27) with the PROCESS add-on for moderation analysis.³⁴ CAT-Q scores were the independent variable, WEMWBS the dependent variable, and ACC the moderator. For the moderation, we mean-centred the variables to avoid potential multicollinearity with the interaction term. Although our research team includes autistic academics, due to funding limitations (this study was RCs Masters’ dissertation), we could only pay to consult an autistic non-researcher at the start of the study on the relevance of the topic to the autistic community and to gather their feedback on the questionnaire. They indicated that the topic was relevant and that the questionnaire was accessible.

Results

Overall, there was a mean CAT-Q score of 131.62 ($SD=19.30$; range 73-171). The mean wellbeing score was 39.16 ($SD=9.76$, range 14-67). The mean autistic community connectedness score was 41.34 ($SD=10.67$, range 15-60). Camouflaging and wellbeing were significantly negatively correlated ($r = -.19, p=.009$) and ACC and wellbeing were positively correlated at a marginal significance threshold ($r=.14, p=.047$). ACC and camouflaging were significantly positively correlated ($r=.20, p=.005$).

In the moderation analysis, the overall model was significant ($R^2=.07, F(3, 192)=4.67, p<.001$). There was a significant positive relationship between ACC and wellbeing ($b=.17, p=.01, 95\%$ Confidence Intervals (CI) [.04, .30]). There was also a significant negative relationship between camouflaging and wellbeing ($b = -.11, p<.001, CI [-.18, -.04]$). However, there was no significant interaction effect ($b<.001, p=.96, CI [-.01, .01]$), indicating no moderation was occurring (Figure 1). The interaction plot shows that when masking is lower, wellbeing is higher - and those with higher ACC have the most positive wellbeing compared to those with medium or low ACC. As masking increases, wellbeing decreases, and although those with high ACC still have higher wellbeing than those with medium or low ACC, the negative relationship between masking and wellbeing still happens – therefore ACC is not acting as a moderator.

[Insert Figure 1 here]

Discussion

This study aimed to investigate the relationship between masking, mental health, and autistic community connectedness. We hypothesised that higher masking would predict poorer mental health, while autistic community connectedness may moderate this relationship. As expected, higher masking predicted worse mental health, but while higher ACC related to higher wellbeing, it did not moderate (buffer) against the negative relationship between masking and wellbeing.

The negative relationship between masking and wellbeing may be difficult to change because it relates to the stigmatisation of autistic people. As argued previously, masking may happen

due to the stigma society attaches to being autistic, given that masking is a strategy often employed to avoid marginalisation, prejudice, and victimisation.^{4,18} Prejudice towards autistic people manifests itself in many ways, for example, in the rapid, negative biases that are formed when non-autistic people form first impressions of autistic people.³⁵ Stigmatising another group involves seeing that group as “other”, fundamentally different, and sometimes as less than human, and we see this dehumanisation not only amongst the general public,³⁶ but within autism research itself.³⁷ Prejudice against autistic people is therefore systemic. If we want to change the negative impacts of masking on wellbeing, we need to create societal level change since masking is often a survival strategy. This change is possible – recent research has shown how training can improve non-autistic people’s attitudes³⁸ and behavioural intentions³⁹. Reducing the ‘double empathy problem’ – mutual misunderstandings between different groups – may also help improve rapport and understanding between autistic and non-autistic people.⁴⁰ Our focus should be on the environmental conditions which promote masking, instead of expecting autistic people to simply not mask.

Since those with higher ACC did experience higher wellbeing overall, this finding shows that ACC still has considerable benefits, and we should continue to find ways to support autistic people to access and explore the autistic community. While previous research has focused on a social identity approach, and the benefits of a strong autistic identity,^{27–29} our research shows how ACC and involvement with the community can predict better mental wellbeing. For example, this involvement could be achieved through online spaces or local, in-person community groups.^{24,25} It is worth noting that some autistic people do not feel part of the autistic community or wish to be a part of it.^{23,41} What is most important is that autistic people have autonomy when it comes to getting involved in the autistic community, and that autistic spaces are run by and for autistic people, and not simply for them.^{41,42}

It is worth noting, too, that we found that greater ACC correlated with *more* masking, and we believe this further supports our argument regarding the impact of prejudice. This finding aligns with previous work which shows that higher autistic social identity also relates to more masking, and that both outness, and concealment or masking relates to worse mental health in the autistic community.^{18,46,47} Those who have stronger connections to the autistic community may be more aware of the systemic barriers to societal inclusion and how society is not ready for unmasked autistic people.⁴¹ Indeed, participants in previous research have talked about how they cannot take the mask off because of the risk of bullying and discrimination.²

Furthermore, those more connected to the autistic community might have increased awareness of masking, specifically because they move more between autistic and non-autistic spaces. For example, in a qualitative case study about an autistic adolescent, he experienced relief upon discovering the autistic community, but then a deep struggle in moving between a community in which he could be more himself, and one in which he could not.²⁵ Looking outside the autism literature, we see this double-bind happening for other stigmatised communities – for people from sexual minority communities, concealing a lesbian, gay or bisexual (LGB) identity is related to poorer wellbeing, and greater outness as being LGB is *also* associated with poorer wellbeing.⁴⁸ Increased outness may result in higher victimisation, but concealment itself is a cognitive burden, and may increase the impact of internalised

stigma on mental health. Taking ownership of a stigmatised identity within a hostile and discriminatory society likely increases minority stress.^{47,49}

We must also scrutinise the stereotypes and discourses around ‘autism’.⁴³ Some of these discourses have gone as far to suggest that ‘community’ is not possible for autistic people.⁴⁴ Autistic people are exposed to a near constant bombardment of deficit-focused rhetoric, negative biases and regular dehumanisation.³⁷ It may not be surprising, then, that some autistic people do not want to associate themselves with the label of ‘autism’ or the autistic community.^{41,45} We must appreciate that some people may have no interest in being a part of the autistic community, and that the autistic community also has systemic issues that make it harder for multiply minoritized individuals to connect (such as racism).⁵⁰ In Westernised societies, we do not foster a positive image of being autistic, or connected to other autistic people, and some might distance themselves from the community in response to this prejudice (a common and well-documented response in other domains).⁵¹

This study is not without limitations: most of our participants identified as female, although we had a reasonable number of non-binary participants compared to previous research. We recruited participants through online spaces (as this study took place during COVID-19), and the internet can provide a safe environment for autistic people to communicate with each other, share experiences and advocate for the autistic community.^{52,53} Autistic community connectedness may therefore be higher in people who frequently use online spaces. Autistic women may also find support via the online autistic community particularly when late diagnosed.^{54,55} Additionally, our study examines the relationship between only three variables – in reality, there are no doubt many other factors which may play a role in the relationship between masking and wellbeing.

Conclusions

Despite these limitations, our study investigates the relationships between autistic community connectedness, masking, and wellbeing, for the first time. While autistic community connectedness does relate to more positive wellbeing, it does not play a protective role against the potentially negative impacts of masking, most likely because it cannot override the stigma and prejudice that exists towards autistic people. We call for a continued focus on the social-environmental factors that relate to masking and more research on how we can create inclusive spaces for autistic people.

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Author confirmation statement

RC and EC conceived of the study. MB provided the ACC measure. RC put the survey on Qualtrics and recruited the participants as part of their MSc Dissertation at the University of Stirling. EC analysed the data and wrote the first draft of this manuscript. MB and RC contributed to subsequent drafts. All authors approved the final version.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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Table 1. *Demographic information including employment, education, ethnicity and country.*

	N (%)
Employment	
Student	64 (32.7%)
Employed Full-time	62 (31.6%)
Employed Part-time	38 (19.4%)
Self-employed	19 (9.7%)
Unemployed	30 (15.3%)
Retired	5 (2.6%)
Carer	9 (4.6%)
Prefer not to say	2 (1.0%)
Highest level of education	
No formal qualifications	3 (1.5%)
High school qualifications	50 (25.5%)
College or diploma or equivalent	20 (10.2%)
Undergraduate degree or equivalent	71 (36.2%)
Masters degree or equivalent	34 (17.3%)
Doctoral degree (PhD) or equivalent	7 (3.6%)
Other qualifications	2 (1.0%)
Prefer not to say	9 (4.6%)
Ethnicity	
Asian	2 (1.0%)
Black / African / Caribbean	1 (.5%)
Hispanic / Latino	3 (1.5%)
Mixed / Multi-ethnic	17 (8.7%)
Native people / Indigenous	2 (1.0%)
White / Caucasian	167 (85.2%)
Prefer not to say	2 (1.0%)
Other	2 (1.0%)
Country	
United Kingdom	91 (46.4%)
Other European countries	11 (5.5%)
United States of America	60 (30.6%)
Canada	14 (7.1%)
Australia and New Zealand	16 (8.1%)
Asia	4 (2.0%)

Figure Legends

Figure 1. Interaction plot showing the relationship between camouflaging and wellbeing, and low, medium and high autistic community connectedness (adjusted values from moderation analysis).

Pre-print