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Abstract

Background: Internalised stigma happens when people incorporate negative stereotypes into their self-concept. In research, some autistic people have shown internalised stigma, which has been associated with heightened psychological distress. Aligned with autistic peoples’ research priorities, this study investigated the impact of stigma and internalised stigma on autistic people’s lives and identities. **Methods:** We used Photovoice method, where people communicate lived experience by taking photographs, and techniques of Interpretive Phenomenological Analysis, which focuses on in-depth individual narratives. **Findings:** Our findings emphasise the relational nature of stigma, highlighting autistic people’s resourcefulness in responding to and managing stigma in complex and context-sensitive ways. Autistic participants also drew on their focused interests and creative expression to actively resist and counter experiences of stigma. **Conclusion:** Future research should focus on targeting stigma amongst non-autistic people, and in exploring autistic people’s focused interests and creativity as potential avenue for improving their wellbeing and fostering a positive identity.

Community Brief

Why is this an important issue?

Internalised stigma happens when people see themselves in a negative light because of others’ bad or false beliefs about them. Research shows that some autistic people have internalised stigma, and that this has bad consequences for their lives and wellbeing. Autistic people in

Scotland have also told researchers that stigma and mental wellbeing are very important topics to investigate.

What was the purpose of this study?

We aimed to see if the way other people talked about autism and autistic people changed how autistic participants felt about life, about themselves, and about autism. We aimed to do this in a participatory way, meaning that autistic participants were actively involved in how the research was done.

What did the researchers do?

We did photovoice with six autistic people living in Scotland. This involved taking photos of their daily lives and talking about these photos in group meetings. We analysed participants' discussions using a technique called Interpretive Phenomenological Analysis, which looks at how participants make sense of their own lived experiences. We also showed participants' photos in a community exhibit and hosted a talk at a local library to raise awareness of stigma within the local community.

What were the findings and conclusions of the study?

Stigma had a bad impact on participants' lives, feelings, and sense of self. Stigma stopped some participants from finding out that they were autistic earlier. Participants also said that building a good sense of self after diagnosis was an ongoing process because of stigma. Participants dealt with stigma using different strategies, depending on which risks and consequences they predicted in each situation. Participants also told us that their interests,

creativity, and sensory differences helped them find and express a more positive and true identity, and they used these as tools to defy stigma.

What is new or controversial about these findings?

Our findings show that the impact of stigma on how autistic people see themselves may be more complex than it appears. For example, choosing to hide autism is not necessarily a sign of a negative sense of self, but may be a practical way to preserve energy and get through difficult situations. Participants' use of personal interests and creative expression to challenge stigma is a new finding.

What are potential weaknesses in the study?

Many participants in this study had other traits that are also stigmatised (e.g., gay, non-binary), making it difficult to know if the experiences they discussed were only because of autism or due to other parts of their identities. The use of photography may have excluded people who do not find this type of communication accessible or enjoyable.

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

This study helps us understand autistic people's experiences of stigma, which is a topic that is important to their daily lives and affects their wellbeing. Based on our findings, future research should focus on shifting negative stereotypes of autism amongst non-autistic people and on exploring focused interests and creativity as ways to improve autistic people's wellbeing and foster a positive sense of self.

1. Background

Autism is not an exclusively natural phenomenon; it is also a label with a meaning largely shaped by non-autistic scholars and practitioners, who have traditionally held epistemic power.¹ Consequently, autism research has mostly operated within a biomedical model where autistic traits are framed as deficits requiring intervention or cure.²

In Scotland, at least 1% of the population is autistic.³ Despite legal protection under the Equality Act, the Scottish Government has noted that many neurodivergent people, including autistic people, report that they do not receive the support and protection from discrimination to which they are entitled.⁴ Recent government efforts have focused on addressing the challenges faced by autistic people in Scotland and improving their inclusion in Scottish society.⁵ Relatedly, recent research shows that autistic adults in Scotland have specific priorities that they would like researchers to address, which emphasise the importance of combatting discrimination and stigma.⁶

Stigma is a process where a more powerful group assigns negative labels to a less powerful group, leading to status loss and discrimination for the stigmatised.⁷ Previous research shows that autistic people are stigmatised^{8,9} and that neurotypical people may perceive autism as something that violates social norms.¹⁰ Studies also demonstrated that non-autistic people formulate rapid negative judgements about autistic people,¹¹ that terms commonly used to describe autism are negative,¹² and that the portrayal of autistic people in the media is predominantly negative.⁸

Stigma has both external components, such as discrimination, and internal components, such as internalised stigma which involves incorporating stigma into self-concept.^{13,7} Autistic people are aware of autism being a stigmatised label,^{1,14} and some have internalised stigma.^{15,16} Across different qualitative studies, autistic people have reported a sense of shame,¹⁷ viewed autism negatively,¹⁸ and discussed how pathologising descriptions of autism influenced self-

perception.¹⁹ Stigma and internalised stigma have also been associated with heightened psychological distress for autistic people⁹ and discussed as a factor hindering their thriving²⁰ and self-determination.²¹

Little research has explored internalised stigma in autistic people and, where it has, it mostly consulted the views of the general population or of parents/caregivers of autistic children, with autistic perspectives being scarce.²² Additionally, a recent study found that two of the top five research priorities of autistic people in Scotland included stigma and wellbeing.⁶ Bridging these two priorities, our research aim is to explore how societal views of autism impacts on autistic participants feelings about themselves, their lives, and about autism – with a particular focus on stigma and internalised stigma. To achieve this, we employed an inductive participatory Photovoice method,²³ where participants communicate lived experience using photographs, and Interpretive Phenomenological Analysis (IPA), where researchers focus on in-depth individual accounts of the participants lived experience.²⁴ Photovoice and IPA have been successfully adopted in combination across social and health research, providing an innovative approach to data collection in research focused on lived experience.²⁵ This is the first study to employ these methods in the investigation of stigma and internalised stigma in autistic adults.

2. Methods

Design

We used an inductive participatory Photovoice method,²³ where participants communicate using photography. Photovoice was developed under the premise that individuals with lived experience have insight into their reality that outsiders lack,²⁶ and it is a promising tool to elicit autistic perspectives as it does not rely only on spoken communication, making it more accessible.²⁷ Photovoice has been widely used in autism research in recent years, constituting an

effective tool for facilitating meaningful participation, yielding in-depth personalised accounts, and promoting participants' empowerment.²⁸

Since Photovoice has an action component,²³ we also hosted a talk at a local library and set up a community exhibit displaying participants' photographs and first-person descriptions of their photos. These events were aimed at the general public, showcasing self-determined autistic narratives and combatting potential stigma within the local community – aligning with Photovoice's aim of creating social change.²⁶ At the start of the project, we consulted participants about the possibility of hosting these optional events, which they expressed enthusiasm for, and explained that they could choose which photos, if any, they wanted to be displayed in the community exhibit.

Prior to the study, the first author completed Photovoice training,²⁹ gaining relevant resources and guidance for this research. The University of Stirling General Ethics Panel (GUEP 2023 14340 10350) granted this study ethical approval. We aimed to recruit a minimum of 4 autistic adults (18 or older) living in Scotland at the time of the study. This range of participants is appropriate for IPA studies which typically incorporate small samples due to the emphasis on in-depth individual narrative.³⁰ Participants were recruited via an online expression of interest form shared on social media, which was available in both standard and 'easy read' versions. The form included key study details and questions about prospective participants' demographics and communication/accessibility needs, enabling us to plan appropriate accommodations. The form also asked whether participants wanted to take part in a group format or in individual interviews. Ten people completed our expression of interest form, and six autistic participants were successfully recruited for this study.

We hired two community consultants to provide feedback and advice on various aspects of this study, aiming to enhance its accessibility and participatory nature. One of the consultants was an autistic academic specialising in increasing accessibility for autistic people in heritage spaces (e.g., museums and galleries) through participatory research. This consultant provided advice and guidance on our community exhibition to make the space and content more accessible to diverse audiences, including autistic people. We implemented several actions aligned with their advice, including offering quiet hours, displaying larger captions in an accessible font, providing more seating space, and presenting the content in alternative digital formats. The second consultant was an autistic person with co-occurring dyslexia who revised our recruitment materials (expression of interest form in both versions) for accessibility and readability. We revised some of the wording and images in our forms to align with this consultant's advice.

Participants

The six participants recruited for this study wanted to take part in a group format. They chose their own pseudonyms (used throughout), and their ages ranged from 18 to 53 years old. One participant made the informed decision to keep their real name, explaining that this felt more authentic. The sample included three women, one genderqueer person, one trans man, and one person who did not disclose their gender. Sexual orientations included gay, heterosexual, bisexual, asexual lesbian, and someone self-described their sexuality as 'autistic.' Two participants were parents of autistic children. Three participants were clinically diagnosed (two in adulthood) and three self-identified as autistic (seeking assessment at the time of the study). Including self-diagnosed participants is increasingly common, as many autistic people either cannot or choose not to pursue diagnosis, particularly intersectionally marginalised people, and researchers argue that self-identified autistics offer valuable insights into diverse social experiences.³¹ As this study

focuses on subjective experience and meaning-making, self-identification is considered sufficient as it shapes participants' inner worlds.

Procedure

This study included four hybrid focus group sessions, attended via Microsoft Teams or in person at the university. The first author (S.D.) led all focus group sessions, with the last and/or third authors being present in all but one session for support. During the first session, the first author (S.D.) introduced the research team, discussed matters of consent and confidentiality, and explained the premises of participatory research and Photovoice methodology. She outlined her interest in understanding how others' attitudes towards autism/autistic people affected participants' feelings about life, themselves, and autism. S.D. explained that this would be explored through participant-taken photographs and group discussions. Then, S.D. opened the discussion for engagement, allowing participants to provide feedback on the proposed plan and/or ask questions. All participants were enthusiastic about the design and topic, and excited to participate. At the end of the session, S.D. presented participants with visual and textual prompts to guide their picture-taking activity (illustrated in Figure 8 in the supplementary materials). As this study is exploratory and inductive, these prompts were open-ended and non-directional.

We used a private page on Padlet - a collaborative cloud-based software that functions as a digital board where users can share content - in between sessions for optional correspondence, which has been utilised in similar research.⁶ This online space gave participants the chance to stay in touch asynchronously if they wished. Some used this space to share and discuss their photos, while others preferred to email them directly to the researchers ahead of group sessions. Each subsequent session (2 to 4) began with a 'check-in' moment regarding the task and any difficulties encountered. S.D. then displayed participants' pictures on her screen, with each taking turns to

discuss their own images. Then, she facilitated group reflections and exchanges using prompts and exercises (see Table 1), and each session ended with time for sharing feedback, queries, and impressions.

Table 1. Prompt questions used in for group exercises during in-person meetings

`Photo` mnemonic³² questions - used to prompt participants to describe and discuss their photos	Questions adapted from Wang's `SHOWED` mnemonic³³ - used to prompt participants' caption-writing exercise
1. Describe your P icture.	1. What do you S EE here?
2. What is H appening in your picture?	2. What's really H APPENING here?
3. Why did you take a picture O f this?	3. How does this relate to O UR lives?
4. What does this picture T ell us about your life?	4. W HY does this problem, situation, or strength exist?
5. How can this picture provide O pportunities for us to improve life?	5. How could this image E DUCATE people about autism?

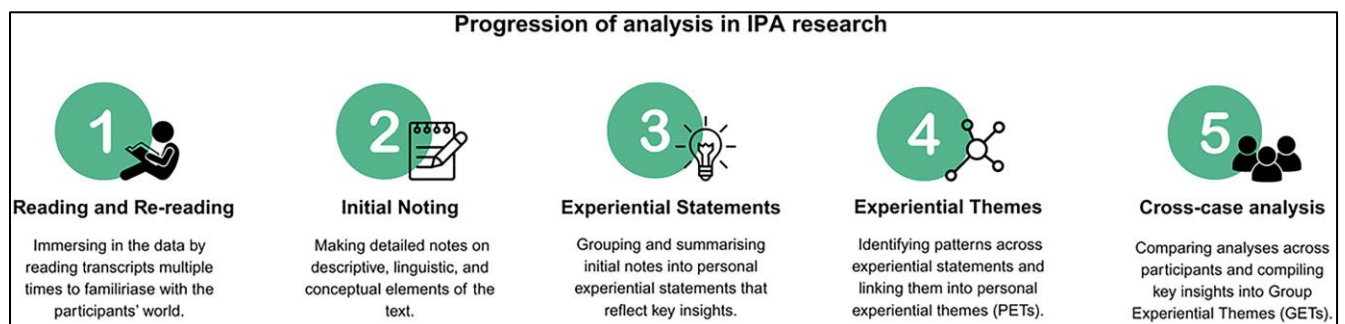
Upon completion of the focus group sessions, we hosted a talk at a local library and set up a community exhibition held at a public arts and culture venue in Central Scotland, which was free to visit for approximately a month. Pictures of these events are included in Figures 10 and 11 in the supplementary materials.

Data analysis

Group sessions were video recorded on Microsoft Teams for transcription purposes. We analysed the transcripts alongside written data from caption-writing exercises and asynchronous study-related discussions on Padlet. While the photographs were an output that helped prompt discussions, we did not directly analyse their visual content (e.g., colour, composition). Although some photovoice research directly analyses participants' photos, in the present study analysing only participants' interpretations of their own photos is more compatible with the idiographic focus of IPA, thereby preserving their voice.

We analysed these data using techniques of IPA,^{34,35} which rests on three theoretical foundations:²⁴ **phenomenology**, exploring experiences as perceived by individuals and free from pre-existing assumptions; **interpretivism**, which recognises that people are meaning-makers, involving a double interpretation as the researcher seeks to understand the participant's sense-making; and **idiography**, which prioritises detailed examination of individual cases before identifying group patterns. To preserve the idiographic aspect of IPA, we intentionally structured the focus groups to ensure that each session included an opportunity for each participant to describe their own photos and experiences individually, in their own words, before the broader group discussions. During IPA's 5-stage analysis (Figure 2), the researcher moves from descriptive levels of appraising manifest data to more abstract levels of interpretation. The analytical process focuses on one participant at a time, and only in the final stage, the researcher conducts a cross-case analysis identifying group patterns and/or differences.

Figure1. Flowchart summarizing the analysis process in IPA. IPA, interpretive phenomenological analysis.



Positionality, Reflexivity, and Community Involvement

Our team included both autistic (S.D. and M.B.) and non-autistic Psychology researchers who share the view that knowledge generated about autism must meaningfully involve autistic people, fostering epistemic justice. Despite the differences in our academic and personal backgrounds, disagreements were resolved through continuous reflexive conversations in group

meetings and a shared understanding that autism is a complex phenomenon intersecting with experiential, social, institutional, and biological dimensions. We used two validity principles (meaning ideas about what counts as valid knowledge). Transgressive validity³⁶ means questioning traditional power structures and recognising that knowledge can be created in creative, non-traditional ways. Rhizomatic validity³⁷ means seeing knowledge as non-linear and interconnected, growing in many directions rather than following a single path. These principles supported neuro-affirming forms of knowledge production that reflexively questioned dominant deficit framings. These principles also aligned with IPA's capacity to foster context-sensitive and anti-reductionist interpretations of autistic identity.

In regard to community involvement, the conceptualisation and data analysis of this study were led by an autistic researcher, and our research questions were oriented by the expressed research priorities of autistic people in Scotland in a community-led study.⁶ The design choices in this study also intended to foster epistemic justice and meaningful participation. This included the choice of a participatory action methodology involving a public talk and an accessible community exhibit centering participants' narrative, consultation with two community members to enhance the accessibility of our recruitment materials and exhibit content, and granting participants a high level of autonomy and input throughout the research process. We offered participants regular opportunities to contribute feedback and suggestions during focus group sessions, the choice of their pseudonyms, preferred mode of participation, and how their photos would be used, the opportunity to report accessibility needs/preferences ahead of the study, to select which (if any) photos they wanted to display in the exhibit, and to write their own captions and descriptions for their displayed photos.

3. Findings

Overview

Our analysis yielded two overarching Group Experiential Themes (GETs), the first of which contained three sub-themes. Below, we have included participants' images to contextualise, illustrate, and frame the analysis where relevant. Captions created by participants themselves were used throughout, and photos not captioned by them were left untitled. All participants consented to the inclusion of their photos in this publication.

Group Experiential Theme (GET) 1. *Navigating contradictions*

This overarching GET entitled '*Navigating Contradictions*' describes how participants reconciled complex and contradictory factors when navigating stigma. In the first sub-theme '*between liberation and loss*', these contradictions are highlighted in relation to diagnosis specifically, with participants experiencing both relief for positively reframing previous experiences, and grief over lost opportunities and denied support. In the second sub-theme '*invisible battles, visible barriers*', the complex effects of stigma were highlighted; while participants discussed both internal and external challenges, they emphasised that the most pervasive consequences of stigma were material and relational, such as discrimination, rather than subjective. In the third sub-theme '*defiance and disguise*', participants talked about employing contrasting strategies to manage stigma, according to an appraisal of external risks (e.g., social rejection) and internal resources (e.g., energy levels). Across all three sub-themes, participants stressed that navigating the world as an autistic person involved a complex negotiation of negative and positive factors. These contradictory and nuanced experiences are captured in Rose's photo below (Figure 2).

Figure 2. Rose's photo entitled "Give up an eye and gain wisdom, but at what cost?"



I remembered a school visit to a Viking Museum where the staff (...) asked who should play each god, and my class said I should be Odin because he sees everything (...). Odin removed one eye in exchange for enhanced perception. I was never able to integrate that well in my class, but I was always pleasantly surprised when they expressed positive feelings about me. (...) I think it taps into a way I feel about autism - I think it's given me perspective that I wouldn't otherwise have, but I've definitely paid a price. (Rose)

Sub-theme 1.1. *Between liberation and loss*

This sub-theme describes how participants' journeys towards understanding and assimilating that they were autistic, whether through formal or self-diagnosis, were layered with complex and often contradictory feelings. Prior to diagnosis, most were exposed to, and

internalised, negative stereotypes of autism. This led to a delayed self/formal diagnosis and an initial hesitation and resistance around the possibility of being autistic:

I'm a very empathetic person. I was like, 'well, autistic people don't have empathy, so I can't be autistic', or 'I had friends and autistic people don't have friends', so that can't be me. Like, just like these horrible stereotypes that I had heard from other people. And then when it was suggested to me that I could be autistic, (...) it was almost as if it was like an insult at first, because if I had heard all these, like, really, stigmatising things about autism and I was like, 'well, that's not me.' (Phoebe)

As they sought support and looked for answers as to why they had always felt different, some encountered a significant lack of awareness from others, including health professionals. For some, this resulted in multiple experiences of misdiagnosis prior to the autism diagnosis. Participants felt that navigating these diagnostic labels—which were often other stigmatised labels including personality disorders, mental health conditions, and neurological conditions—was damaging to their self-concept and reinforced a sense of inadequacy and defectiveness. The subsequent lack of appropriate support and the lingering feeling that something was still ‘wrong’ generated feelings of shame and weariness:

I didn't get a diagnosis till the age of 40. I'd been misdiagnosed with, like, loads of other things before, including my favourite, which was frontal lobe epilepsy(Ash).

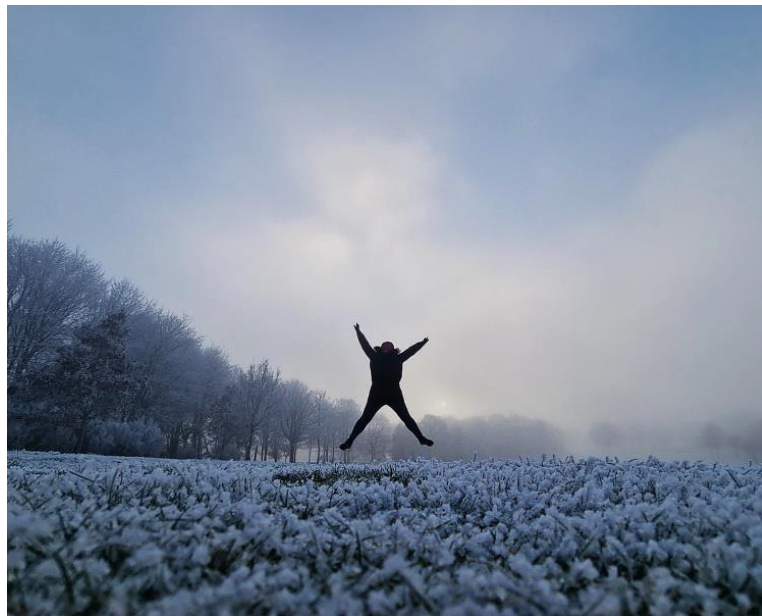
You see women who get diagnosed late with autism, and it's like, these are their notes, basically, like, trauma, or this, or she might be bipolar, or she might have this (...) personality disorder, or whatever, and I guess over years it just made me withdraw more and more for people, and I just became more and more ashamed (...) I didn't seek help properly and I didn't know what was going on. (Rose)

Participants described that being exposed to positive portrayals of autism and finding what being autistic meant to them personally was helpful in promoting self-understanding and acceptance. This awareness allowed them to deconstruct internalised stereotypes and normalise their experiences with the understanding that these stemmed from a different way of functioning, as opposed to an inherent fault that they were to blame for:

I for a long time thought I was really bad at communication and, like, conveying my feelings, but after learning I just conversate in a different style to how people typically talk, I'm not actually bad at communicating my thoughts. (Andrew)

This unburdening self-acceptance experienced after diagnosis is depicted in the photograph entitled 'Acceptance' taken by Aurora (Figure 3) below.

Figure 3. Aurora's photo entitled "Acceptance."



I always liked things that people used to find weird. And all the time I was hearing 'you are weird, Aurora, you are weird'. (...) now that I am aware about autism and I am aware that it is perfectly okay to be me, that it's more like the acceptance of what I am. I'm

happy the way I am, and I don't care now if people think I'm weird. If you think I'm weird, fine, that's your opinion. That doesn't affect me as much as it used to. (Aurora)

Despite this relief experienced through self/formal diagnosis, many participants stressed how their post-diagnostic journey was not entirely positive. Diagnosis was not a 'magical solution' to their problems, and significant challenges persisted, such as communication gaps, difficulties navigating relationships, sensory and/or environmental barriers, and inner echoes of their previous negative self-perception. Similarly, participants expressed a sense of grief and frustration over the opportunities lost and the support that they could have accessed if they had been diagnosed earlier, stressing that it was hard to wonder how their lives could have been:

(...) if I had been diagnosed earlier because I would've been able to deal with the idea that I was different, instead of wondering why everywhere I went there seemed to be social rejection. (Rose)

If we had back then when I was a child the knowledge of autism that we have now, I would have been diagnosed as a kid and that would have also avoided a lot of things. (Aurora)

Overall, the sub-theme '*Between liberation and loss*' highlights the tensions and the complex subjective journey of autistic self-recognition, underscoring the alienating impact of social stereotypes and how they can act as a barrier to self-understanding. Participants' accounts revealed initial feelings of confusion and resistance upon considering an autistic identity, indicating that they possibly possibly internalised autism stigma prior to diagnosis due to neurotypical stereotypes of autism, which they later found not to be true. Self-understanding and exposure to alternative framings of autism, in contrast, provided relief and facilitated the development of a more positive self-concept. Despite this newfound understanding, post-

diagnostic challenges remained a reality, with many experiencing frustrations over lost opportunities and continued barriers and difficulties in navigating a world that remained largely unaccommodating.

Sub-theme 1.2. *Invisible battles, visible barriers*

Despite attributing more responsibility to external barriers in their experienced challenges after diagnosis, some participants still dealt with lingering internal effects of a long-standing sense of inadequacy – highlighting how the process of moving towards a healthier autistic identity is not always a linear progression, but an ongoing reconciliation. Aurora, for instance, despite highlighting how she felt more comfortable with herself after self-diagnosis, still felt responsible for some challenges in social interactions. Years of navigating unclear communication made her hypervigilant and led to overthinking, rumination, and self-doubt:

Sometimes I just overthink too much. Things are simple, but I'm so used to (...) people not being clear. So sometimes the person maybe is being clear, but I overthink so much (...). Or people give me mixed signs, or I just process the information wrong. A troubled mind let's say. (Aurora)

Similarly, Rose expressed how years of social isolation, and of relying exclusively on herself due to lack of support, made it hard to deconstruct ingrained beliefs and behaviours, including self-criticism and perfectionism, which once allowed her to cope but were also detrimental to her self-concept. Operating for a long time on the premise that something was inherently ‘wrong’ with her and that it was her responsibility to fix it, Rose expressed struggling to be compassionate towards herself:

I'll do my best to be myself and to actually tell people when I need help with things and to not get annoyed at myself for needing things. But it's really hard to unpick all of

that. Because (...) I've had years of asking for help and it being very ineffectual or not there.

(Rose)

Despite these internal struggles, participants stressed that stigma mostly affected their lives on an external level instead. Autism stigma was deeply intertwined with lived and material challenges, such as establishing positive relationships, navigating social interactions, and carrying out daily tasks due to the exhaustion from masking autism – which is expressed by Phoebe below:

I am exhausted from having to pretend not to be autistic at work. (...) Autism stigma affects me constantly, and has real impacts on my everyday life leading to me feeling exhausted and, ultimately, a messy wardrobe. (Phoebe, talking about her photograph of a messy wardrobe)

Participants expressed that, even if they did not see themselves through the lens of stigma and moved away from negative self-talk, other people still applied negative stereotypes to them. Participants felt that they were not seen for who they were, but through a neurotypical lens biased by stereotypes. This often prevented them from establishing and maintaining relationships, as illustrated by Andrew's picture (Figure 4).

Figure. 4. Untitled picture taken by Andrew.



(Figure 4) reminds me of the question (...) of how others' perceptions of me [affect] my perception of myself. My answer to this would be that they don't. They are the jam, and I am the marmite. (...) When someone has, for example, a view that autistic people are childish, (...) because the other person can't see outside that lens, it makes it hard for me to feel as if I am being seen for who I really am, and that is what in turn [affects] the relationship. I think this effect on the relationship is possibly what you see [affecting] autistic people's mental health as well. (Andrew)

Overall, the sub-theme ‘*Invisible battles, visible barriers*’ highlights the dual impact, subjective and material, of stigma on autistic people’s lives. Participants largely recognised external barriers—such as lack of appropriate support and widespread misconceptions—as the primary sources of their challenges. However, many continued to grapple with internal challenges, such as rumination and self-criticism. Despite this, the main impacts of stigma were material and

affected their daily lives, especially in relation to how others perceived and responded to them. These external relational barriers often led to withdrawal, social isolation, and intense emotional labour which, in turn, had significant detrimental effects on subjective wellbeing. As participants dismantled previously internalised negative stereotypes and moved toward greater self-awareness and acceptance, real-world barriers were still encountered daily and were a source of intense frustration and weariness. Thus, subjective and material effects of stigma did not occur in isolation but rather in interaction, highlighting stigma's relational and dynamic nature.

Sub-theme 1.3. *Defiance and disguise*

This sub-theme pertains to participants negotiating multiple factors when responding to stigma. Although some adopted certain coping techniques in a more consistent way than others, the group overall described adapting the way they coped with stigma through a complex appraisal of subjective factors (e.g., personal energy levels) and external circumstances (e.g., who they were talking to). Thus, there was an accentuated sense of intentionality in how participants disclosed their diagnosis and responded to stigma, with a continuous weighing up of stakes and consequences:

I kind of try and gauge the situation, but sometimes I do comment, sometimes I don't because it's exhausting. (Phoebe, on responding to stigma)

Some participants felt that concealing their diagnosis and modifying their behaviour, which they often referred to as 'masking', was necessary to fit into social circumstances and avoid rejection in the short-term – even if it coincided with reinforced negative feelings in the long-term. This simultaneously adaptive and harmful self-modulation is illustrated in Rose's photo (Figure 5) below.

Figure. 5. Untitled photo by Rose.



I used to just sit in school with this palpable blanket of sadness and worry, and I'd just look at my desk when people made fun of me. (...) I'd just let myself sink into a kind of numbness where I [felt] joined to the chair and unable to really move out of it. I worried about every movement of my body, always observing the way I stood up from my desk, was I walking ok, did I look weird? I can still sometimes get like this when I'm feeling bad.
(Rose)

To avoid negative consequences, participants also expressed intentionally abstaining from challenging stigma and/or expressing their personal opinions, despite an inner awareness that others' attitudes and views were wrong. This deliberate avoidance was more related to self-preservation than to participants' own morality and self-concept, as illustrated in the photo entitled 'Necessary, evil' by Phoebe below (Figure 6).

Figure 6. Photo entitled "Necessary, evil" by Phoebe.



Whenever I leave the house, I substitute my tangle for my scrunchie. I do this as almost every time I have used a stim toy in public I have received strange looks. Even though they are very similar in shape and size, it is somehow far more socially acceptable to fidget/stim in public with a scrunchie? This picture symbolises a few things for me: masking, making myself less comfortable for the sake of others, the complete lack of sense/logic behind what is socially acceptable, particularly for autistic/disabled individuals. (Phoebe)

Thus, more passive or introspective attitudes towards stigma were motivated by a desire for social harmony, or simply served as a pragmatic approach to self-preservation and energy management. Some expressed, however, that these strategies could be conflicting on an internal level as there was dissonance between expressing their authenticity versus obtaining social acceptance, and a mismatch between inner awareness and the unaccommodating external reality:

The thing I have struggled with since the diagnosis is you're encouraged to think (...) that you should just be accepted and things should be different and work around you a little, but I've kind of struggled with the idea of, if people are socially rejecting you, maybe they're not always doing it for like conscious reasons, and are there ways that I could modify my behaviour that would make it easier for me to have social relationships, but then at what point are you not being truthful? (Rose)

In contrast, participants also described situations where their mere personal acceptance was enough to insulate them from detrimental inner effects of stigma, preserving and protecting their sense of self. Some participants reported positively reframing their autistic identity by recognising their strengths, embracing authenticity, and humanising their differences, as represented in Ash's photo below (Figure 7).

Figure 7. Ash's photo entitled "To misquote Luke Skywalker...Autism is strong in my family, my father had it, I have it, my sister has it. You have that power too..."



We [Ash and children] all got our own lightsabers and lanyards that we keep on the back of the door... We're a bit like the Skywalkers, but with slightly more stimulating... And it seems a bit of a cliché, but I think it kind of hopefully humanises it a bit more... If I can be deeper there, it's challenging. It's not that it's taking away the seriousness of it, but it's adding a human element that makes it “hang on. It's just kind of normal”, if that makes sense.

Some opted to be more open and vocal about their autistic status and personal views, advocating for themselves and challenging the stigmatising attitudes they encountered, either in a lighter tone through humour and irony, or more directly by openly disagreeing with others. Ash, specifically, described viewing himself as a social ‘agitator’, finding energy and empowerment in

challenging societal narratives rather than feeling drained by this process – a purpose that extended to his professional career as well as personal life:

I did kind of 20 years teaching groups to work with arts and play development for special needs and social work groups and things like that. So, I kind of come at it from the point of view of almost like the agitator, if that makes sense. I was committed from almost an agitation point of view that, (...) rather than a draining thing to kind of combat people's issues to how they see it, I almost see it as that's something that almost powers me up, if that makes sense. Kind of trying to fight the stereotypes of how people see autistic people.

(Ash)

The sub-theme '*Defiance and disguise*' explores the nuanced, strategic, and deeply personal ways autistic individuals managed stigma in their day-to-day lives, revealing a constant negotiation between resistance and concealment, authenticity and adaptation. Participants described a dynamic, relational, and contextual process of decision-making shaped by factors such as personal energy levels, perceived social risk, and contextual cues, resulting in the intentional modulation of self-expression. Passive attitudes towards stigma and acts of 'disguise' were less about shame and more about self-preservation. Others managed stigma through self-acceptance or active strategies like advocacy, finding strength in challenging stereotypes and subverting social norms. In sum, this subtheme illustrates how stigma management is fluid and context-dependent, and that choosing when to 'show' or 'shadow' reflects adaptation to an unaccommodating world—not necessarily a question of authenticity.

Group Experiential Theme 2. *Passion, Creation, and Perception*

GET2 entitled '*Passion, Creation, and Perception*' highlights how expressing themselves authentically – whether through uncensored sensory engagement, creativity, or pursuing and

sharing passions and interests – was very important to participants’ lives and wellbeing. This authentic expression also served as a tool to resist neurotypical stereotypes, antidote stigma, and define their identities on their own terms. Creativity, sensory engagement, and personal interests were often entangled and interconnected elements, as many participants described that their ‘special interests’ related to creative endeavours incorporating sensory elements (e.g., music, art), and constituted a more intuitive means of communication. Some participants also expressed that their motivation to join this study was directly related to the visual and creative nature of Photovoice methodology, which was accessible, intuitive, and enjoyable for them:

I like arts and photography. It's one of my hobbies, actually. So, when I saw that (information about this study), I was like, 'that's perfect.' ” (Aurora)

My twin daughters were nonverbal till seven, so they always used photos to communicate and made films. Our youngest started speaking at 15, so he still, to this day, uses a lot of visual stuff (...), so it was kind of second nature to do it. (Ash)

Participants’ interests enhanced wellbeing by facilitating enjoyable sensory engagement and/or fostering states of flow and immersion. This allowed participants to escape an often-overwhelming external reality marked by stigma and misunderstanding, finding refuge in a safe introspective space:

Real life in a neurotypical world can be annoying, boring, very limited. Music and my drawings can make me travel to lots of different times in my history, different locations, universes and even to my very vivid dreams. It is also a way to express myself when words fail. (Aurora)

Participants' interests also helped them feel connected to the world and to others, as they were used for socialising more confidently and establishing meaningful friendships with like-minded people:

We were wearing Star Wars t-shirts, so I went over and went 'You like Star Wars, I like Star Wars, you can be my friend'. And 47 years later, we're still friends. And our entire basis of our relationship is based around films. (Ash)

Importantly, creativity and personal interests allowed participants to understand themselves outside a neurotypical gaze, to find and share their strengths, and to feel proud of their identities – encouraging some to use them as tools to challenge stereotypes and to advocate for themselves and others:

People say that art can give you a voice, but I've found a fair few of my [art] commissions give a voice to others too... And I think it kind of breaks that whole idea of autistic people not being very empathic or very sympathetic, that you can produce a project like that. (Ash – on an artistic project about the experiences of refugees)

This identity celebration was also incorporated in how participants presented externally, with some wearing clothing, objects, and tattoos related to their interests and values as a means of affirming their authenticity – as seen on Arrietty's photo (Figure 8) below.

Figure. 8. Untitled photo by Arrietty.



I know a lot of people (...) that have like pins and collections and things that they really love but they don't really show it off in public because they're just worried that it seems childish or it's just revealing something about themselves that they don't want. But (...) I've always found like a lot of pride just being able to show off like 'yeah I love these pieces of media and I've loved them for several years' or I'm not like afraid to show things that are making up a really big part of me. (Arrietty)

Thus, engaging authentically with their senses, interests, and creativity fostered connection to oneself and wellbeing on an internal level, as well as opportunities for social connection, engagement, and advocacy on an external level. They also antidoted internalised stigma, allowing participants to find joy, recognise their strengths, and define themselves outside a neurotypical gaze. Despite consistently experiencing stigmatisation and discrimination, participants found and/or created authentic ways to express themselves and celebrate their authenticity and abilities, facilitating a more positive self-regard. This resilience highlights autistic agency and

resourcefulness, also stressing how their lives can be full of meaning, purpose, and joy despite stigma and adversity.

4. Discussion

Six autistic participants contributed photos and reflections on how others' beliefs and attitudes towards autism influenced how they felt about their lives, about themselves, and about autism. The first overarching GET '*Navigating contradictions*' captured the complex and multifaceted nature of participants' experiences. In the sub-theme '*Between liberation and loss*', participants described mostly internalising stigma prior to diagnosis, and some expressed an initial resistance of autistic identity due to absorbed negative stereotypes. Exposure to alternative understandings of autism and self-understanding helped participants develop more positive identities outside the neurotypical gaze and deconstruct internalised stigma. Some participants also stressed, however, that moving from a long-standing negative self-perception to a positive identity was an ongoing process.

Our findings add nuance to the stigma models of Goffman³⁸ and Link and Phelan⁷ by demonstrating that internalised stigma may occur prior to labelling, such that the discrepancy between stereotypes and the individuals' own experience prevents self-identification. Recent literature on stigmatised identities has shown that stigma can indeed be internalised prior to labelling, with a complex journey of unpicking and deconstructing it after self-identification. Participants in a study by Huang et al,³⁹ for example, described absorbing negative autism stereotypes before being diagnosed and, while diagnosis facilitated self-understanding and acceptance, negative beliefs did not immediately subside.

In '*Invisible battles, visible barriers*' participants highlighted stigma-related challenges and stressed how the most pervasive were indeed extrinsic and relational, as opposed to solely

subjective. Internal positive shifts in identity did not change external barriers limiting opportunities for social connection and acceptance. Participants often experienced and anticipated rejection in social situations, and exhaustion from concealing their autism to fit in. Internalised stigma itself was not the main factor contributing to internal distress, but rather the emotional and energetic toll stemming from external barriers such as discrimination, which in turn led to internal challenges like poorer wellbeing, difficulties completing daily tasks, exhaustion, isolation, and withdrawal. This emphasises the dynamic nature of stigma, where subjective and material dimensions may be reciprocal.

Link and Phelan's⁷ concept of *status loss and discrimination* highlights the material consequences of stigma beyond subjective experience. Link et al.⁴⁰ also noted that individuals may anticipate stigma based on past experiences, leading them to withdraw or modify behaviour as self-protection. This is a dynamic we found in our data, showing that isolation and withdrawal can be both outcomes of stigma as well as coping strategies (with subsequent negative impacts on wellbeing). Similarly, Botha and Frost⁹ found a strong correlation between everyday discrimination and expected rejection among autistic participants. Our findings build on this, suggesting that repeated discrimination reinforces expectations of rejection, prompting further withdrawal and isolation.

Recent findings within the autism literature echo our participants' experiences of relational barriers and social disconnect despite self-acceptance, indicating that some autistic people can be content with their identities while still facing external rejection – highlighting how stigma operates relationally. In a study by Botha, Dibb and Frost,¹ autistic participants were frustrated by how, even when they personally embraced their autistic identity, others often could not see past their diagnosis. Han et al.'s²² systematic review of autistic people's experiences of stigma also

highlighted how many participants did not personally view their autism negatively but still faced misunderstandings, exclusion, or pity from others. This discrepancy between self-regard and others' perceptions generated a sense of social disconnection. Thus, autistic people have reported often being perceived in a negative bias with neurotypical stereotypes that do not match their own experiences. This highlights how interventions aiming at social education remain crucial, rather than solely focusing on personal coping strategies for the stigmatised. Accordingly, in a subsequent study by Han et al.⁴¹ autistic participants believed that the primary focus of any intervention should be on changing non-autistic people's attitudes instead of helping autistic people themselves cope with stigma.

In the sub-theme '*Defiance and disguise*', participants employed different strategies to cope with stigma, including masking autism, abstaining from challenging others' attitudes, being selective and intentional in disclosure, practising self-acceptance, and challenging/subverting normativity. This was a dynamic approach involving the appraisal of multiple contextual factors and risks. Both Goffman's³⁸ and Link and Phelan's⁷ stigma models account for this, acknowledging that people may switch strategies according to perceived risk. Recent literature highlights the inherent trade-offs of stigma management strategies, with autistic people reporting that all had some degree of negative consequences to manage.^{16,1} Similarly, our participants expressed the contextual importance of masking autism but also said that it can be exhausting and create dilemmas of authenticity – echoing Hull et al.'s⁴² study where participants reported that the main consequences of camouflaging their autism were exhaustion and feeling 'fake'.

Our data adds to, and differs from, literature on other stigmatised communities. For instance, a study related to sexual minorities found that revealing one's stigmatised status (outness) was related to higher wellbeing.⁴³ Additionally, in individuals with serious mental illnesses (SMIs),

avoidant coping strategies such as camouflaging were associated with higher internalised stigma.⁴⁴ Yet, more unites these communities potentially than divides them; in another study of sexual minorities researchers found that outness was associated with both increased wellbeing *and* increased discrimination,⁴⁵ while other research shows that both outness and concealment of sexual minority status are associated with increased depressive symptomology,⁴⁶ which Botha and Frost⁹ also found in a sample of autistic adults. While our participants demonstrated that choosing to mask is not necessarily related to one's self-concept but mostly due to relational barriers, there is a somewhat interconnected experience to managing stigmatised and "concealable" identities, and that there is always nuance in managing other people's expectations of these kinds of identities and violence attached to disclosure. Relatedly, it is worth noting that many autistic people, including our participants, have multiple coinciding minority identities⁹ (e.g., gender and sexual minorities), in that the experiences of stigma faced by these communities may be multi-layered and interconnected.

In the second GET entitled '*Passion, Creation, and Perception*', participants emphasised the role of authentic self-expression in their lives. Creative and sensory engagement through visual media, art, and personal projects was described as central to identity, wellbeing, and self-determination, as well as a tool for resisting and counteracting internalised stigma. These passions fostered self-understanding and connection with others, also serving to subvert normativity and challenge stereotypes and misconceptions. They enabled participants to define themselves on their own terms, fostering self-determination and allowing participants to find/create joy despite stigma.

Traditionally, autism literature has framed autistic people's interests in ways that reify impairment,⁴⁷ necessitating intervention and/or extinction.⁴⁸ Other research,⁴⁹⁻⁵³ however, highlights that focused interests play a positive role in autistic people's lives, constitute areas of

strength, and are central to autistic wellbeing. Our data aligns here, showing multiple benefits of engaging with their interests, including as a tool for identity pride, advocacy, and, ultimately, as an antidote to internalised stigma. Creativity and interests helped participants with reframing to non-stigmatising self-understanding.

Bross et al.⁵⁴ found that many autistic participants described masking or hiding their interests to avoid shame and rejection, despite stressing how these generated significant benefits. Participants who experienced more bullying related to their interests had higher depression and anxiety, while those lacking support reported higher stress. This highlights the persistence of deficit-based stereotypes in contrast to autistic people's own positive experiences. The theory of *monotropism*, developed by autistic scholars, presents focused interests as a value-neutral cognitive style rather than a negative deficit.⁵⁵ The gap between neurotypical perceptions and autistic lived experience underscores the need to amplify autistic narratives and scholarship to challenge stigma.

Strengths and Limitations

A potential limitation in this study relates to our participants' demographics, as they held multiple intersectional labels related to other minority identities (e.g., gender minorities) that also face stigma. These identities, in addition to autism, may have simultaneously impacted their experiences, making it difficult to determine the extent to which they are unique to autism itself or a complex by-product of negotiating multiple stigmatised identities. However, it is worth noting that autistic people frequently report non-conforming gender and sexual identities,⁵⁶ alternatively making our sample representative of this natural population characteristic, which is inherently tied to the dynamic nature of stigma. While we took active steps to preserve the idiographic focus of IPA and collect rich individual-level data about participants in this study, the use of focus groups

may have obscured these nuances in participants' diverse characteristics and experiences, given that the discussions predominantly revolved around the shared characteristic of autism. Using photovoice resulted in both strengths and weaknesses in this research – for our participants, who expressed an affinity with visual communication, Photovoice facilitated meaningful participation and yielded insightful contributions due to its flexibility and accessibility; however, it may also have excluded those who find it less accessible.

Conclusion and future research recommendations

Our findings show that stigma's impact on autistic people's lives stems from dominant neurotypical stereotypes that misrepresent the actuality of autistic lived experience, but which have real, material effects. This highlights the relational nature of stigma and the need for research and practice to adopt frameworks that affirm autistic ways of being. Future research should develop interventions targeting false stereotypes among neurotypical people and promoting autistic self-determined narratives, including those of intersectionally-marginalised autistic people who are traditionally under-represented and may deal with increased levels of stigma-related stress.⁹ One example of this relates to media representations of autism,⁸ which remain largely stigmatising, stereotypical, and lacking nuance and diversity in portrayal,⁵⁸ while constituting a central source of “information” about autism, shaping beliefs and attitudes in the general population.⁵⁹ Future research should also further explore focused interests and creativity as pathways to foster wellbeing, self-determination, and positive identity formation for autistic individuals.

Authorship statement

S.D. conceptualised this study, led data collection, analysed data, and wrote the original manuscript under the supervision of C.J., C.G., M.B., and E.R. All authors discussed the analysis

reflexively in focus group sessions and contributed to reviewing and editing the original manuscript. C.J. and C.G. participated in data collection during focus group sessions.

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Supplementary material

Figure 9. Example photography prompt given to participants during focus group sessions

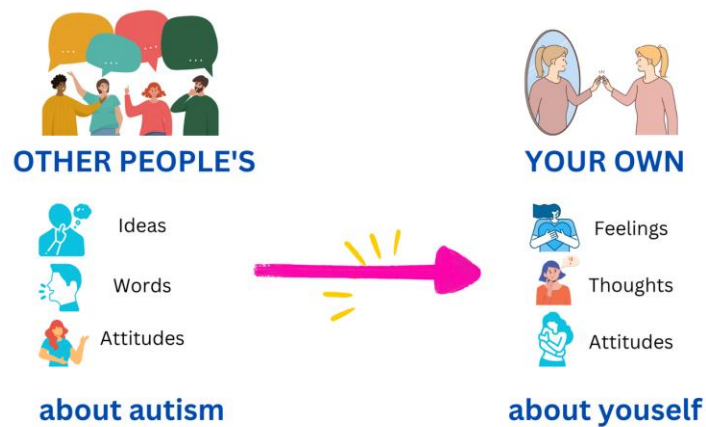


Figure 10. Participants' photos displayed during a public talk event at a local library



Figure 11. Gallery wall displaying participants' photos in the community exhibit



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