




Article

'Let Us Be the Art, Not Just the Entertainment': A Participatory Zine-Making Study Engaging Autistic Women and Non-Binary People in Discussing Media Representations of Autism

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Abstract

Autistic people experience social stigma, which involves facing negative or false social stereotypes. A prevalent stereotype of autism in society is that it is a male condition, which has led to most traditional representations of autism across different types of media (e.g., characters in films and TV) being predominantly male-focused. In this study, a group of autistic women and/or non-binary people were recruited to speak about how they perceived media representations of autism, as their gender identities did not fit this traditional gendered stereotype. Participants shared their experiences through group discussions and a zine-making activity, where they created different forms of artwork that were then compiled into an independent community booklet and displayed in an exhibition in Central Scotland. Participants' group discussions and descriptions of their artwork were analysed using IPA techniques, yielding two experiential themes. Participants discussed negative experiences with dehumanising media accounts of autism, which displayed autistic people as a stereotypical 'other', as well as positive experiences with humanised media accounts, which prioritised autistic lived experience in a more authentic and relatable way. Our findings highlight that the media can positively impact autistic people's lives when representations centre on autistic lived experience, which fosters connectedness, autonomy, and self-understanding. Alternatively, this impact can be harmful when media accounts are stigmatising and dehumanising, which generates significant material and subjective challenges.

Keywords: autism; stigma; media; zine-making; participatory action research; Interpretive Phenomenological Analysis



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1. Introduction

1.1. Autism and Stigma

Autism is a life-long neurodevelopmental disability that influences sensory processing, cognitive style, and social interaction [1,2]. Autism, however, is not a strictly natural phenomenon representing an underlying structure of nature. It is also a socially constructed label carrying a meaning mostly generated by non-autistic researchers and practitioners (such as psychiatrists, clinical psychologists, and special educators), who have historically held epistemic power—meaning power to generate knowledge that is deemed true

or scientific [3,4]. Consequently, autism research has traditionally operated in a biomedical model that frames autistic people's differences as deficits or pathologies requiring elimination or intervention [5]. However, more recently, researchers have discussed how studies adopting this deficits-based biomedical framework often cultivate a dehumanising rhetoric towards autistic people [6], contributing to the dissemination of stereotypical and stigmatising views.

Stigma occurs when a more powerful group assigns negative labels to a less powerful group based on perceived differences, leading to status loss and discrimination against the stigmatised [7]. There is evidence in the autism literature that autistic people are socially stigmatised [8,9], which is significantly linked to heightened psychological distress, as well as reduced wellbeing and quality of life in this population [3,9]. Examples of this are illustrated in research showing that neurotypical people formulate rapid negative judgements about autistic people [10], and that many commonly used descriptors of autistic people are negative [11]. These patterns of stigmatisation are further reinforced by media representations [9], which often present narrow or stereotypical portrayals of autism and shape public perceptions, especially among those with limited direct contact with autistic people [12,13].

1.2. Media Representations

Media representations of autism have the potential to either positively or negatively impact lives, serving to promote awareness or to promulgate negative and/or false stereotypes and thereby perpetuate stigma [14]. Indeed, research has demonstrated that media shapes attitudes towards autism [15,16], constituting one of the main available sources of autism information for the public [17,18]. A recent rise in representations of autistic people in entertainment media has both positive and negative impacts—when educational, they can foster understanding of autism; when portrayals are inaccurate, however, they can perpetuate stigmatisation—for example, storylines which reduce an autistic character to a plot device or to an amusing 'other' [19].

Amongst common stereotypes, the belief that autism is a male condition is prevalent. This stereotype is reinforced by some research operating within the biomedical model of autism, which has proposed that autistic people have an 'extreme male brain'—in that their brains are largely wired to 'systemise' as opposed to 'empathise' [20]. In contrast, other research argues that lower rates of autism diagnosis in women do not necessarily reflect lower prevalence, but rather result from multiple, interacting factors [21]. These include the fact that autistic women reportedly mask autism more (meaning hiding their autistic traits) [21,22], especially in conventional situations where they attempt to get by as socially 'appropriate' [23]. Additionally, the female autism presentation may be different from the male, but questionnaires commonly used to diagnose autism were developed and validated with autistic men and may not be effective in capturing alternative profiles, including women and other gender identities.

Misconceptions of autism, including gendered stereotypes, have been widely represented across different types of media. In cinematic media, for instance, research has identified a focus on homogenous male characters [14], such as the protagonists in *Rain Man*, *The Big Bang Theory*, and *Atypical*. A literature review [14] analysing representations of autism in fictional media and their impact on viewers' understanding found that current portrayals of autism in cinematic media (e.g., films, series) remain problematic overall. Representations focused largely on autistic people with complex support needs, or on stereotypical profiles of autistic savants. The authors highlighted that a more diverse and intersectional demographic (e.g., autistic women, non-binary people, non-white people) is traditionally underrepresented, also indicating limited evidence of spectators demon-

strating increased understanding of autism after exposure to this media content. Recent research [24] also shows that most quotes from British newspapers assigned autism and autistic people low warmth and competence—meaning that they were not described as ‘friendly’ or ‘kind’ (warmth), nor as ‘knowledgeable’ or ‘efficient’ (competence)—which predicted prejudice against them. Interestingly, a literature review [13] found similar negative connotations in fictional cinematic media (e.g., TV shows, films) and newspapers but noted that representations of autism in fictional literature (e.g., novels) were more diverse and positive, whereas social media representations appeared more supportive.

Misheva [25] argues that mainstream gendered stereotypes, including the cliché autistic male ‘savant’, like Sheldon Cooper from *Big Bang Theory*, do not reflect the diversity of the autistic population, reinforcing problematic misconceptions. Ultimately, they perpetuate the “simplistic and misleading stereotype of autism as a ‘male’ condition. . . , which renders invisible the diverse experiences of many autistic people who do not fit this very restrictive mold, regardless of gender” [25], p. 15. Thus, stereotypes of autism as a ‘male’ disorder can be a barrier to diagnosis for autistic women, while encountering representative portrayals of autistic women in the media is beneficial in helping them identify traits in themselves and facilitating diagnosis [26]. Relatedly, autism is present across a diverse distribution of gender and race [27,28], and recent evidence from a study conducted in Sweden also shows that the male-to-female ratio of diagnosis has significantly decreased in the past 35 years, with more women getting diagnosed as autistic—especially in adulthood [29]. Importantly, it has been estimated that 80% of autistic women are undiagnosed at the age of eighteen [28], and that autistic women are 13 times more likely to die of suicide than non-autistic women [30]. There is limited research into the experiences of trans and/or non-binary autistic adults, but studies indicate that non-binary autistic people have a decreased sense of belonging [31], poor rates of mental health, and high rates of discrimination and victimisation, with anti-autistic discrimination uniquely predicting anxiety and post-traumatic stress [32].

1.3. This Study

The aim of this study was to investigate autistic women and non-binary people’s first-person accounts of the following:

- (1) How they feel about media representations of autism, covering both fictional and non-fictional content;
- (2) How this impacts their lives.

To our knowledge, no studies have specifically explored how autistic women and non-binary people feel about this topic using Participatory Action Research (PAR), a community-centred approach that co-produces knowledge about participants’ experiences to promote social change [33]. Thus, we engaged a group of autistic women and non-binary people in discussing their experiences through the co-creation of a ‘zine’—a small, independently published booklet that compiles various artistic and visual media (e.g., illustration, collage, poetry). In academia, zine-making originated as a scientific activity in feminist pedagogy [34] and has been recognised as both a pedagogical tool and a research tool across disciplines [35]. Zine-making has been previously effectively used in autism research to elicit autistic people’s experiences of social connection during the COVID-19 pandemic [36].

Zines provide a platform for social commentary, with minority groups using them for political activism, to promote self-determined narratives, and to elicit individual lived stories [35]. In addition to producing a visually engaging and widely accessible output, zine-making fosters a creative and connective space for exchanging experiences and perspectives among participants. By centring the lived experiences of participants with multiple stigma-

tised identities (autistic, woman, and/or non-binary), we believe that Participatory Action Research methods, such as zine-making [37], are powerful tools to foster epistemic justice in autism research. Moreover, because this method does not rely solely on written or spoken communication, as do alternative methods (e.g., interviews, focus groups, social media), it enables diverse, flexible, creative, and accessible self-expression for autistic people, a group with varied communication needs and preferences [38].

2. Materials and Methods

2.1. Methodology

We used an inductive participatory zine-making method [36,37], in which participants discussed their lived experiences in group meetings and co-produced a zine, and Interpretive Phenomenological Analysis [39] (see analysis section below). Zines are booklets composed of different media and forms of expression (written, visual, artistic), according to participants' preferences and creativity. As with other participatory visual methods, such as Photovoice [40], we used participants' visual artwork to elicit personal and group reflections and discussions about media representations. Prior to the start of data collection, the first author undertook training in the facilitation of zine-making activity in a scientific context.

2.2. Recruitment and Ethics

Participants were recruited via an online expression of interest form shared on social media (Facebook, Instagram, X), available in both a standard and an accessible 'easy read' version, in accordance with NHS accessibility guidelines. The expression of interest form contained key information about the study and questions regarding participants' demographics and communication/accessibility needs, enabling researchers to plan appropriate accommodations before data collection began. The form also included a section in which participants provided informed consent, including regarding how their data (photos and quotes) would be used, prior to participation. Participants were told that they could withdraw from the project at any time, without penalty, during the course of the focus group sessions, and that upon conclusion of these sessions, they had up to two weeks to withdraw their data. Ethical approval was granted by the University's General Ethics Panel.

2.3. Participants

Six participants were recruited, which is a typical sample size for studies adopting Interpretive Phenomenological Analysis (IPA) frameworks [39], due to its idiographic nature—meaning that there is a deeper focus on each participant's individual narrative. Two participants dropped out of the study after the first session for personal reasons and commitments, in that data pertaining to only four participants is presented here. This final sample is still typical and suitable for IPA research [39]. Participants were given the opportunity to choose pseudonyms (different names) for themselves to preserve anonymity and confidentiality in the research outputs. However, after thorough discussion about potential identification risks and ethical considerations, some participants made the informed decision to preserve their real names, stating that they were generally very open about their autistic identities and lived experiences, and indicating that keeping their real names in this project felt more authentic. This preference was confirmed on two separate occasions—verbally during focus group sessions and via individual correspondence with participants after data collection concluded.

Our participant sample included two self-described autistic women, one non-binary woman, and one non-binary person. Three participants were clinically diagnosed with autism (two in adulthood) and one self-identified. Three participants reported co-occurring

ADHD (two formally diagnosed). Including self-diagnosed participants is an increasingly common practice in autism research, with researchers arguing that they offer valuable data regarding diverse social experiences within the autistic population, especially when many autistic people do not have access to diagnosis due to systemic barriers (e.g., long waiting times, costs of private diagnosis) or choose not to pursue it [41]. As this study focuses on subjective experience and meaning-making, including self-diagnosed individuals is appropriate, as self-identification shapes participants' inner worlds and influences how they interpret lived experience.

2.4. Design

This study included five in-person focus group sessions, with all participants attending at least four. These sessions took place in a meeting room at a public arts and culture venue in Central Scotland. The first author led all sessions, with at least one other co-researcher present; the second and last authors attended four of the five sessions each. In the first session, the first author introduced the research team, discussed consent and confidentiality, and explained the principles of participatory research and zine methodology—including the proposal for a potential (and optional) community exhibit displaying participants' artwork at the end of the project. The first author expressed interest in understanding how participants perceived media representations of autism and how these perceptions affected their lives. After these explanations in session 1, the first author opened the discussion for feedback. Participants confirmed their enthusiasm for the proposed design, topic, and structure, as well as the possibility of participating in a collaborative group exhibit.

Every subsequent group session was divided in two parts: in the first half, participants engaged in a 45 min discussion about media representations, followed by a 10 min break; in the second half, participants engaged in 50 min zine-making activity to produce artwork for the collective zine (Figure 1) based on any ideas/insights generated by the initial group discussion, followed by a closing 10 min chat about what they were working on. The first author prompted discussions with open-ended and non-directional questions (e.g., “would you change anything about how autistic characters are portrayed in the media?” and “What would your ideal character be like?”). However, these prompts were optional, and discussions were primarily shaped by participants' own interests, given the method's open-ended and participatory nature [35]. To preserve the idiographic nature of IPA [39], each focus group intentionally included time for participants to take individual turns to describe and discuss their own artwork and experiences. In sessions 4 and 5, the first author also proposed exercises in which participants wrote individual captions and descriptions of their own artwork created during the zine-making process (Figure 2). Participants' self-written captions and descriptions for their artwork are used in the Findings section of this study and in the community exhibit, preserving their voice.

2.5. Data Analysis

Data were analysed using IPA [42,43], an idiographic research method that rests on the premise that individuals construct unique subjective meanings from their lived experiences, which are, in turn, contextualised by broader factors such as history and culture [44]. Group sessions were audio recorded for transcription, and the data analysed in this study comprised both transcripts of group discussions and participants' written descriptions of their artwork. Zine-making was the research tool through which participants' experiences were elicited and discussed verbally, with the artwork itself serving as an output for dissemination and for framing the analysis presented in our findings. However, the artwork itself (e.g., colour, composition) was not directly analysed in this study—only participants' descriptions and discussions of it. This also aligns with IPA's idiographic

focus [39], where we analysed participants' own interpretations of their work rather than directly interpreting it on their behalf.



Figure 1. Zine-making activity in progress.

- What do you see here?
- What's really happening here?
- How does this relate to my life?
- Why does this problem, situation, or strength exist?
- How could this image educate people about autism?

Figure 2. Caption-making prompt presented to participants—adapted from Wang's [40] "SHOWED" mnemonic.

IPA is rooted in three theoretical foundations [45], namely **phenomenology**—which focuses on a subject's own perception of phenomena/experience; **interpretivism**—which recognises that individuals construct a subjective interpretation around their lived experiences, requiring a double-hermeneutics process where the researcher interprets the participant's interpretation; and **idiography**, which focuses on analysing individual cases as opposed to solely identifying group patterns. IPA has been argued to be an appropriate analytical framework for participatory autism research that elicits first-person perspectives [44]. While IPA and zine-making have not been combined in research to date, IPA has been widely and effectively used alongside other visual action research methods, such as Photovoice, in autism research [46,47]. Since we are using artwork created by participants as an

elicitation tool, like photography in Photovoice, the use of IPA in this study is well justified, as it aligns with our research aims and methodology.

IPA comprises five stages of analysis (detailed in Figure 3), in which the researcher moves from initial descriptive appraisals of the data to more abstract levels of interpretation. The first four stages of analysis are conducted individually for each participant, in accordance with this method's idiographic focus. Only in the final stage is a cross-case analysis conducted to identify broader group patterns, where the researcher looks for similarities and differences across individual participant cases to develop overarching themes. This stage culminates in the generation of Group Experiential Themes that represent shared meanings and experiences among participants. An example of this analysis process is included in Table 1.

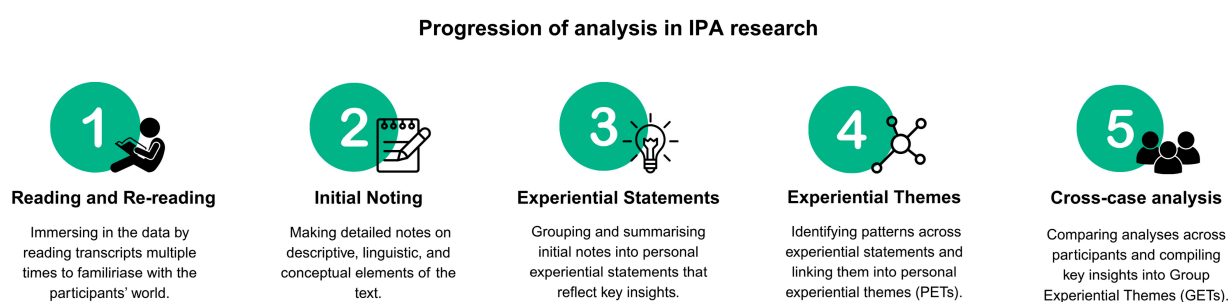


Figure 3. Analysis process in IPA, extracted from Dantas et al. [46].

2.6. Positionality, Reflexivity, and Authorship

Our team comprises both autistic and non-autistic Psychology researchers with expertise across Social, Community, Developmental, and Cognitive Psychology. The diversity in our lived experiences and epistemic views fostered nuance in our discussions and analyses. We acknowledge that autism sits at the intersection between a neurodevelopmental condition and a social identity; therefore, we believe that discussing the challenges experienced by autistic people should incorporate a holistic, ecological lens. The first author conceptualised the study along with the second, third, and last authors. All authors contributed to the production of the original manuscript. The first author conducted the analysis individually and engaged in continuous reflexive practice drawing on transgressive validity, which challenges dominant power structures and posits that validity can be established through creative and non-traditional approaches [48]. All authors discussed the findings reflexively. Generative AI was not used in this research.

2.7. Community Involvement

The research aims of this study were informed by the research priorities expressed by autistic people in Scotland in a community-led study, namely “knowledge and attitudes towards autistic people” and “issues impacting autistic women” [49], p. 2184. The conceptualisation and data analysis of this study were led by an autistic researcher, and our design choices, including a participatory action methodology, were intended to foster epistemic justice and meaningful participation. Autistic participants in this study were granted a high level of autonomy and input, being offered alternative forms to express interest in taking part, telling us about their accessibility needs/preferences ahead of the study, having regular opportunities to contribute feedback and suggestions to the project, co-designing our zine and exhibition, and choosing how they wanted their work to be used and displayed. For instance, participants selected which artworks to include in the exhibit and wrote captions and descriptions of their work for inclusion in the exhibit and the zine. Additionally, an autistic consultant specialised in heritage spaces was hired to help make our community exhibit accessible to diverse audiences, including autistic visitors.

Table 1. Example of partial IPA 5-stage analysis.

Participant's Quotes	Initial Noting	Experiential Statements	Experiential Themes	Group Experiential Theme
<p>Andrea—Quote 1. <i>[in] Love on the Spectrum, you always see the people's mums, or dads, or caretakers, whatever. On any other dating show, how often are you seeing the person's mum?</i></p> <p>Andrea—Quote 2. <i>I think it's almost impossible to think of something that doesn't become sexualised. Yet, (. . .) when it's like an autistic show, or with autistic characters, it never has that element.</i></p>	<p>Descriptive notes: Quote 1. Comment on the prevalence of caretakers/parents in the portrayal of autistic adults on TV. Quote 2. Comment on the lack of sexuality attributed to autistic characters.</p> <p>Linguistic notes: Quote 1. The use of a question seems to challenge or provoke the interlocutor to reflect on a contrast that is evident and important to the speaker. Quote 2. The words "impossible" and "never" stress a stark opposition.</p> <p>Conceptual notes: Quote 1. Participant implies that dating is often an autonomous adult experience for non-autistic people, but, in contrast, it is tied to a parent's/caretaker's perspective or consent for autistic people, minimising their autonomy. Quote 2. The ubiquity of non-autistic sexual portrayals versus the complete absence of sexuality in autistic characters stresses the lack of common and relatable human experiences/traits, such as sexuality, being afforded to autistic characters.</p>	<p>Quote 1. Questioning autistic adults' lack of autonomy in dating shows compared to non-autistic.</p> <p>Quote 2. Questioning the lack of sexuality attributed to adult autistic characters on TV compared to non-autistic.</p>	<p>Autistic people are infantilised and denied autonomy in media portrayals.</p>	<p>'No one is the same thing all the time'—dehumanisation and stigmatisation in the media.</p>

Table 1. Cont.

Participant's Quotes	Initial Noting	Experiential Statements	Experiential Themes	Group Experiential Theme
<p>Charlie—Quote 1. <i>I remember reading a textbook, something in a textbook, where it [autism] was compared to sociopathy. They were like, 'Oh, this bit of the brain that's kind of associated with empathy is smaller in autistic people and also in sociopaths'. And I'm like, okay, I mean, that doesn't actually mean anything, but people who read that are obviously going to draw conclusions.</i></p> <p>Charlie—Quote 2. <i>Quite often when writers set out to make an autistic character, they'll look at a lot of autism stuff that's (...) more of the kind of like newspaper articles and stuff like that. That's very like "this is what autism is", and then that'll become their thing for a character.</i></p>	<p>Descriptive notes: Quote 1. Comment on the social repercussions of autism being compared to sociopathy in a textbook. Quote 2. Comment on writers basing autistic characters on selective types of information that result in one-sided portrayals.</p> <p>Linguistic notes: Quote 1. The use of hypothetical quotes seems to suggest/imagine the person behind the text, whom Charlie disagrees with, in a sort of imaginary dialogue. Quote 2. The expression "of the kind" suggests that there are different "kinds" of knowing autism. The expression "this is what autism is" seems to imply that autism is being defined in a totalising way by an anonymous other.</p> <p>Conceptual notes: Quote 1. Dehumanising information that is deemed 'scientific' about autism, even if not representative of how autistic people feel, influences how others perceive them (e.g., having no empathy). This is akin to the dynamics of stigma. Quote 2. Writers base autistic characters on reductionist information that wipes out nuance in portrayal, keeping them in a less "human" place.</p>	<p>Quote 1. Questioning the negative social consequences of 'scientific' dehumanising knowledge about autism, without autistic input.</p> <p>Quote 2. Attributing the lack of authentic autistic characters to writers' exposure to stigmatising and dehumanising autism information.</p>	<p>'Scientific' portrayals of autism can be dehumanising and generate stigma.</p> <p>Autistic characters are often reduced to less human portrayals.</p> <p>Reductionist and stigmatising rhetoric in science, the media, and social perceptions of autism are interconnected.</p>	<p>'No one is the same thing all the time'—dehumanisation and stigmatisation in the media.</p>

3. Findings

Analysis using IPA techniques yielded two overarching Group Experiential Themes (GETs), which depict participants' feelings about media representations of autism and their perceived impacts. These themes are described in detail below, with example quotes illustrating the analysis. Zine artwork was included where its descriptions are relevant to the analysis, exemplifying how participants chose to portray their thoughts visually in the zine. While we did not analyse or interpret the artworks' visual or artistic content (e.g., composition, colour), they are connected to and illustrative of the analysis, given that participants' written descriptions and oral discussions about their artwork are integrative to our dataset. Participants' self-generated captions were preserved throughout, and artworks without captions were left untitled.

3.1. GET 1: 'No One Is the Same Thing All the Time'—Dehumanisation and Stigmatisation in the Media

This GET, named after a quote from our participant Andrea, encapsulates participants' perception of current media representations of autism across both fictional (e.g., TV and films) and non-fictional domains (e.g., news articles) as overall dehumanising and stigmatising against autistic people. Participants expressed that media representations of autism tend to wipe out nuance, personhood, and individual variability—focusing instead on fixed accounts that standardised and juxtaposed autistic people as a homogenous, less human 'other'. Participants Charlie and Rhiannon discussed how non-fictional media, especially news articles and newspapers, usually focus on etiological and technical aspects of autism (e.g., potential causes, functioning levels), as opposed to the idea of a differently wired brain (rather than a pathological one). They felt that this promoted a narrative of fixing a 'flawed' and 'defective' autistic individual, instead of acceptance and inclusion. Participants suggested that the technical vocabulary, impersonal tone, and scientific rhetoric often used in these media turned autism into a 'thing that is talked about', instead of an experience lived by real people. This created a sense of objectification and dehumanisation, where the propagation of a standard, fixed version of autism wiped out nuanced accounts and experiences that could otherwise describe and validate autistic people's embodied reality.

A lot of the non-autistic view of autistic people out there (. . .) is very focused on negatives, or the like different levels and stuff, rather than it just being a different brain. It seems to be very focused on how to change it, rather than how to just accept it. (. . .) The vaccines, those kinds of things, it doesn't have to be factual for it to be in a textbook or in the newspaper or on the TV. Even research. So, I think a lot of people still are looking towards that rather than the real reality of it.—Rhiannon

Participants expressed that this fixed and over-simplified account of autism also happens in entertainment cinematic media, including films, TV shows, and reality shows. Autistic characters are often reduced to either a stereotypical 'quirky' self, or to portrayals of autistic people with complex support needs, which did not reflect the diverse experiences within the autistic population. Participants said that it was rare to find autistic people portrayed with emotional and moral depth, commenting on how characters rarely assumed more complex roles such as the villain/anti-hero, or less infantilised accounts where characters displayed, for instance, autonomy or sexuality:

In "Love on the Spectrum", you always see the people's mums, or dads, or caretakers, whatever. On any other dating show, how often are you seeing the person's mum?/[In "Atypical" there's this scene where Sam] is looking at the penguins in his favourite place, (. . .) and everybody's like, oh my god, where is he? And he's an adult at this point, and

everybody's freaking out because they don't know where he is, and then they find him and he's just chilling, looking at something that he enjoys.—Andrea

Sexuality was an aspect discussed more often in relation to female autistic characters, with participants noting that while most non-autistic female depictions in the media are easily sexualised, autistic women are either portrayed with no sexuality or with very niche or unusual preferences:

It's almost impossible to think of something that doesn't become sexualised. Yet, when it's like an autistic show, or with autistic characters, it never has that element.—Andrea

This was also exemplified by the mention of the character 'Lily' in the TV show *Sex Education*, whom participants felt was autistic despite not being explicitly mentioned. Lily fantasised about having sex with aliens and non-human creatures, which participants felt was portrayed with exaggeration. Interestingly, some participants also said that 'autistic coded' characters—those not expressly autistic but who display autistic traits—were often more relatable, as they were afforded more nuanced personalities. Participants supposed that expressly labelling a character as autistic was deemed 'different enough' by writers and creators to give these characters a niche, turning them into a 'trope' that was denied the complex subjectivity and holistic personhood often seen in non-autistic characters:

When writers set out to make an autistic character, they'll look at a lot of autism stuff that's more of the kind of newspaper articles, that's very like 'this is what autism is', and then that'll become their thing for a character. (. . .) If you're writing a character, you're focusing on their personality and what they're like as a person. And then they also just so happen to have some autistic traits, it just feels quite often more real because they're not trying to live up to the 'we need to make this character clearly autistic.—Charlie

Participants also expressed that characters often needed to be identifiably autistic to the neurotypical gaze, thus conforming to predictable stereotypical accounts prevalent in society:

Looking at typical characters, look how broad the range is. They can be anything, anybody, anywhere. Yet, when you see autistic characters or any sort of disabled characters, they tend to fit inside this one small box. (. . .) Neurodivergent people aren't just neurodivergent, they are an entire person beyond that.—Andrea

Thus, participants defended that having autistic producers, writers, and/or actors involved in the production of these media would offer a more authentic and diverse representation of autism. These critiques are commented on below, in relation to Andrea's artwork entitled 'Paper pages, empty spaces' (Figure 4).

This piece (Figure 4) is a commentary on how media can tend to rely heavily on tropes of autism written by non-autistic creators. The identity of a minority defined by the words of the majority. We must redistribute the power to a diverse group of people. I hope autistic people can see that they can be any role, whether that be sexual, confident, quiet, intense, demure. You are everything that you want to be.—Andrea, about the artwork depicted in Figure 4

The pervasive fictional representation of a one-dimensional autistic character, in its unnatural yet easily identifiable otherness, perpetuated and confirmed the impersonal 'autism' portrayed in non-fictional media. Because a one-dimensional person is an abstract, unrelatable possibility, this representation confined autistic people to a less human place:

If they say this character's autistic, everything they do must come across as stereotypical. I think that could probably play a role in people feeling like, 'well that doesn't feel human', so I don't relate to that because you're constantly the same type of person.—Andrea

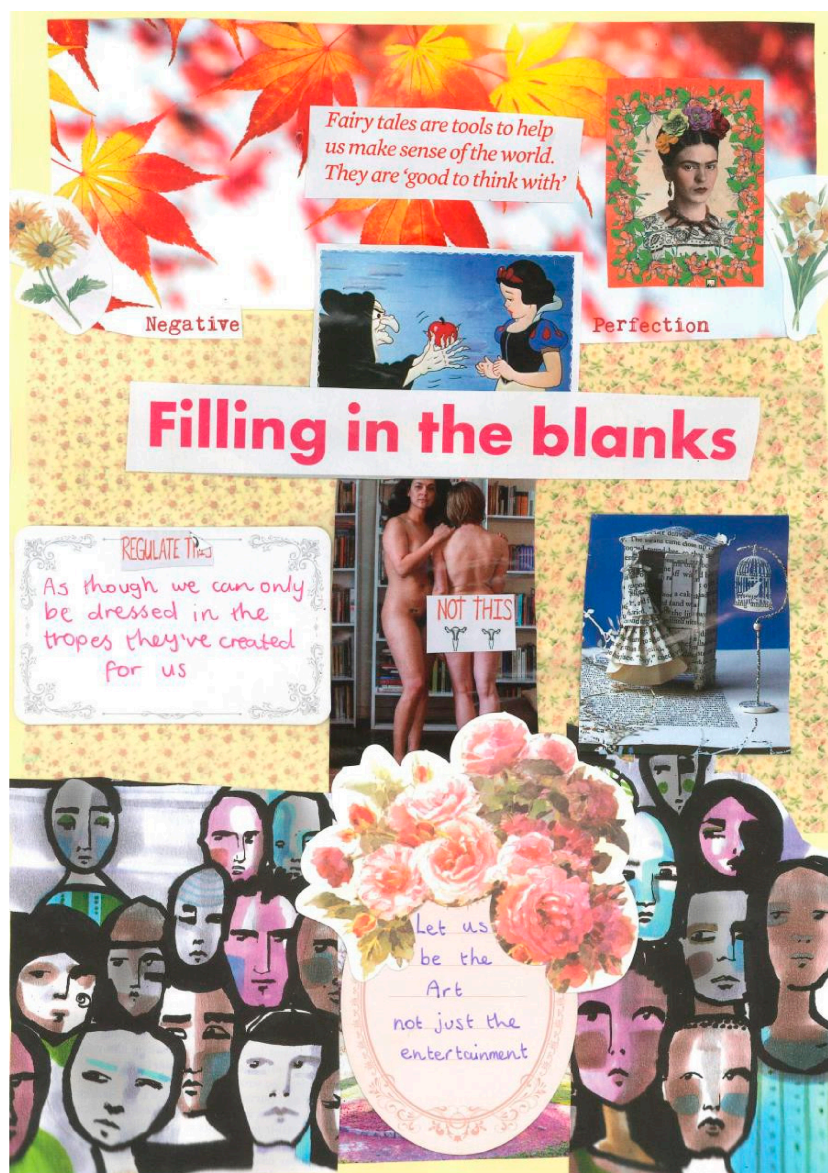


Figure 4. Artwork entitled 'Paper pages, Empty Spaces', by Andrea.

This self-confirming rhetoric, in turn, preserved a deficit-based view of autism as the predominant representation in the eyes of the public, perpetuating stigma and dehumanisation against autistic people. The reproduction of old findings based on a deficit-framing of autism in science, as well as the propagation of familiar stereotypes in media, seemed to serve as self-confirmation of autistic people's separating 'otherness', justifying othering attitudes towards them. This critique is illustrated in Charlie's quote below, regarding the artwork depicted in Figure 5.

On one side, we have a lion representing some autism researchers with all this text about research—"replicating the old", "old tricks". And on the other side, I've got this little bird, which I chose as a contrast to the lion. [Through] our eyes, the world looks different—the bird represents autistic people. I think they (bird and lion) would have a different perspective on life. I meant both sides of this work as separate pieces that are not interacting—because that's how a lot of autism research works. It's all about replicating old findings and not really talking to autistic people.—Charlie, about the artwork depicted in Figure 5

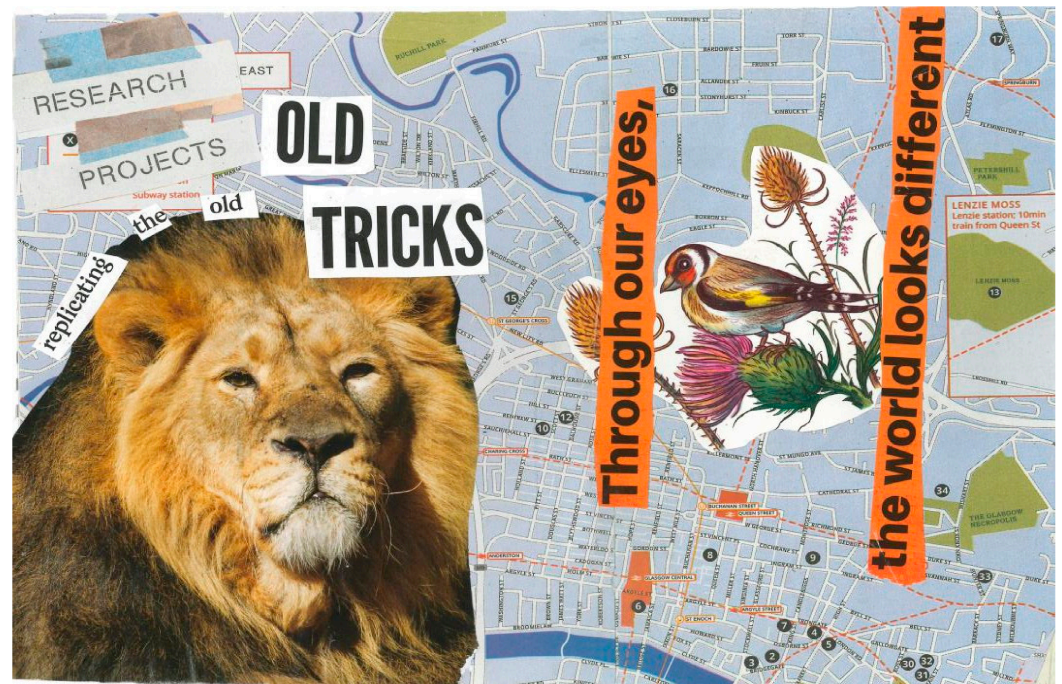


Figure 5. Untitled artwork by Charlie.

Participants also discussed real-world impacts of these stereotypical, dehumanising and/or stigmatising representations of autism in the media. Amongst these, Isla highlighted that stereotypes in the media contributed to a late diagnosis for both her and her daughter, with autism being a possibility she often dismissed despite other people's suggestions because their experiences did not match the expected portrayal of autism she knew from media accounts:

Probably the way autism is talked about in the media and in non-fictional ways (...), news, has really impacted probably a late diagnosis for [my daughter] because people would say to me and I'd be like: 'don't be bloody ridiculous, of course she's not.' It's a shame. But because of what I had read, or what I had learnt, (...) I've never recognised it in myself, never recognised it in her. If I had been able to look at that differently, with different knowledge, factual, proper knowledge, then things could have been different.—Isla

Similarly, Andrea described that her caretakers could not identify that she was autistic due to a lack of information on how autism can manifest in girls:

I think that media obviously shapes public opinion on things, and I think that public opinion then shapes how we didn't receive diagnosis, because if our parents were aware of how the things manifest, then it would be easier for them to see it. (...) The lack of representation in the media led to a lack of knowledge within (...) my caretakers, and then they couldn't understand what to look for.—Andrea

Overall, in the GET 'No one is the same thing all the time—dehumanisation and stigmatisation in the media', participants critiqued media representations of autism that were stigmatising, dehumanising, and did not match their lived reality. Overall, this GET also suggests a 'feedback loop' between science, media, and public views. Participants reflected on the detrimental impact of these dehumanising representations, discussing who they served and to whom they catered. If these representations were quickly identifiable to the neurotypical gaze, but were ultimately not relatable to autistic people themselves, participants suggested that they served as self-confirming justification for the existing

negative bias against autistic people that is prevalent in society, which often originates and/or is reinforced in science too.

3.2. GET 2: ‘Precious Jewels of Self-Knowledge’—Endorsing Self-Determined Narratives

This GET, named after a quote from our participant Isla, describes participants’ encounters with media that were representative of their lived experiences, and the impact this had on their lives. Participants emphasised that constructing their own subjective, self-determined version of autism had often been made difficult by the pervasive stigmatising media portrayals discussed in GET1, which not only influenced other people’s views of autism but also impacted their own experience of self-understanding:

Getting a diagnosis meant looking back on my life and who I thought I was in a new lens and wiped a lot of “me” away. Because of the stereotypes and very rigid ideologies of autistic people I often find my version of autism is brushed off and my struggles minimised. (. . .) I’m still trying to figure out what being autistic means to me because it’s often denied.—Rhiannon

However, participants also discussed the positive impact of encountering alternative first-person accounts of autism, either on social media or through their own efforts to find literary and scientific work authored by autistic people. They felt that this was helpful in countering an internalised sense of inadequacy generated by traditional, alienating media accounts. Alternative portrayals on social media, in books by autistic authors, and/or in research papers rooted in a Neurodiversity understanding of autism were described as more realistic and value-neutral, recognising autistic experiences in a humanising as opposed to a moralising tone:

I’ve read papers that they can talk about some of the really difficult things about autism, but they do it in a way that doesn’t feel dehumanising.—Charlie

Participants were critical of how social media can lead to an oversimplification of information, with bite-sized content and “hot takes” (e.g., posts where people say, “if you do these three things, you are autistic”, as discussed by Andrea). However, there was an overall positive attitude towards social media, as these online spaces allowed participants to find other autistic people, communities, and advocates who voiced relatable experiences as expressed in the quotes by Rhiannon and Charlie in the quotes below:

That’s the one place (social media) where you can find real autistic people’s experiences and real autistic people. (. . .) There are a lot of newspapers, textbooks, by non-autistic people who are just writing about what they’re seeing rather than other people’s experiences. All of my understanding of autism comes from social media.—Rhiannon

I was 15 or 16 when I came across autistic advocates and stuff. I think it was on Tumblr, and it was the ‘actually autistic’ hashtag. And that was the first time I was like: ‘first of all, this is an experience that’s shared’, because people told me I was autistic, but I didn’t know what that meant for me. They would be like ‘you’re autistic, that means you annoy us.’ But then there’s all this stuff about difficulty identifying emotions and sensory stuff. And I was like ‘this is autism. I’m not just a weirdo.’ Yeah, it was always nice just to have words for it and then to be able to be like ‘it’s not just me.—Charlie

Exposure to humanised and first-person representations fostered a sense of both connectedness and autonomy, as encountering others who shared their experiences counteracted feelings of isolation and separation, while facilitating self-understanding and encouraging authenticity. Participants emphasised the importance of having self-determination in describing their own experience of the world, which was made possible by existing online

spaces where they felt safe and to be their true selves. This is illustrated in Rhiannon's quotes below, regarding the artwork entitled 'Camouflage' (Figure 6):



Figure 6. Artwork entitled 'Camouflage', by Rhiannon.

Within this image (Figure 6) you can see multiple texts that explain masking and its detrimental [effects]. People stuck in their own world and facing their everyday mountains. And the ability of our minds when they are nurtured and supported in our growth by others rather than pushed into hiding. Being autistic in a world that was not made for us can be a very lonely and isolating experience. Everyday can feel like an uphill battle with the most simple of things. Having to camouflage your heart and soul and mask your true self to feel safe and accepted in the world is exhausting. Mirroring others just to feel 'normal' is a cage. Finding people you don't have to put on that camouflage for is true safety. A safety that I find in social media.—Rhiannon

The reported benefits of encountering these media representations went beyond subjective realms of reconstructing identity and self-acceptance, with material and real-world repercussions too. Charlie, for instance, highlighted how finding vocabulary that matched their own reality—including terms created by autistic people—allowed them to turn experiences that felt abstract and inarticulate into something real and shared, which is empowering when communicating with others and advocating for themselves:

When I found out like alexithymia (...) and like the double empathy problem... Actually having words for it that I could use to talk to like therapists or psychiatrists; and even if they didn't understand what I meant, they could at least then do their own research.—Charlie

Despite these benefits, participants emphasised that first-person accounts of autism were often dismissed by traditional scientific and otherwise non-fictional media as an 'unreliable' source of data—when, ultimately, these accounts were the most helpful in their lives. Thus, they described a fundamental contradiction in how media considered 'factual'

often focused on abstract, impersonal ‘data’, while media considered ‘anecdotal’ showcased lived experiences that were real:

People quite often like dismiss stuff about social media and be like ‘oh, well, that’s not, you know, that’s anecdotal’. First of all, anecdotal? That’s still people, people talking about their experiences is factual.—Charlie

Overall, the GET ‘*Precious jewels of self-knowledge*’—self-determined narratives of autism highlights how inclusive and humanised representations of autism made a positive impact on participants’ lives—facilitating meaningful connection, self-understanding, and autonomy, while also antidoting and preventing internalised negative stereotypes. Participants emphasised how humanising autism did not mean denying its struggles or painting a rose-tinted picture of being autistic; rather, it meant having real faces and stories behind representations, as opposed to impersonal and othering ‘data’. In the quote below, Isla comments on the importance of self-knowledge derived from defining what autism meant to her personally, including both beautiful and chaotic aspects of personhood, which she depicts in her artwork titled ‘Deep rooted’ (Figure 7):



Figure 7. Artwork entitled ‘Deep rooted’, by Isla.

This art (Figure 7) represents the deep and complex mess of roots—like veins—carrying lifeforce and toxins in communicating the experience of ‘being different’. The misunderstanding others’ reality and the experience of their world. The inner deep-rooted conflict and chaos that holds precious jewels of self-knowledge.—Isla

3.3. Analysis Overview

In summary, GET 1 ‘No one is the same thing all the time’—dehumanisation and stigmatisation in the media’ and GET 2 ‘Precious jewels of self-knowledge—self-determined narratives of autism’ show the contrasting nature and impacts of dehumanised versus humanised media representations of autism. While dehumanising accounts, emphasised by participants in GET 1, reinforced stigmatisation and constituted an obstacle to participants’ self-understanding, humanised first-person accounts of autism discussed in GET 2, conversely, offered the possibility of reframing autistic identity in a more authentic and empowering way. Taken together, these themes highlight the role media representations play in the lives of autistic women and non-binary participants, and its potential to both facilitate and hinder autistic people’s self-understanding, self-determination, and societal acceptance depending on how it is done. To disseminate this message among local community members, we organised a group exhibition in which participants’ artwork, reflections, and the finalised zine were displayed.

4. Reflections on the Research Process and Community Exhibit

In the final session of our study, participants shared their experiences of the research process and their hopes for what our group’s exhibit would achieve. Regarding the research process, the primary challenge discussed was the substantial time commitment required for this study. Apart from this issue, all participants reported very positive experiences, stating that they wished our meetings would continue and describing the research environment as enjoyable and mutually supportive. Participants also discussed the value of research incorporating autistic people’s own voices, as discussed by Rhiannon:

I think things like this are really helpful. It starts a conversation and gets people in the same room, talking about things maybe they would not otherwise.—Rhiannon

When sharing their hopes for the exhibit, participants said they would like autistic visitors to feel represented and connected to the content, while also hoping that non-autistic visitors—especially stakeholders such as mental health professionals—would benefit from the alternative format of the knowledge presented and be inspired by a new perspective. This is described in Isla’s quotes below:

I would like for [autistic] people coming in and connecting with it, and going ah!, finding a sense of relief. That this is being put across in a different way that they get and feel connected to./For me, the things that have ‘shifted’ something were most unexpected things. . . Sometimes you come across something that is just done in a completely different way. And it just changes your perspective on something. That is what I would like.—Isla

Four original artworks selected by participants, photographs of the research process, and the finalised zine containing all artworks were displayed at a community exhibit (see Figure 8 below), along with participants’ self-generated captions and descriptions. This exhibit took place at an accessible public art gallery in Central Scotland, and was open for a month, attracting approximately 200 visitors. Upon consulting with an autistic accessibility advisor specialised in museum and gallery spaces, we also adjusted how the content was displayed to the public. This included using larger captions in accessible fonts, offering alternative digital formats for the exhibit content, providing more seating space, and organising weekly quiet hours with fewer visitors and reduced sensory input. We also

had a ‘creative room’ with a public book where visitors could anonymously contribute notes, impressions, and artwork. Over 50 visitors shared informal feedback about their visits, including many impressions of it as ‘thought-provoking’ and ‘representative’. While the informal feedback from visitors was overwhelmingly positive and encouraging, we acknowledge the possibility of bias, given that these comments were left in a public space where visitors may be less likely to express negative thoughts.

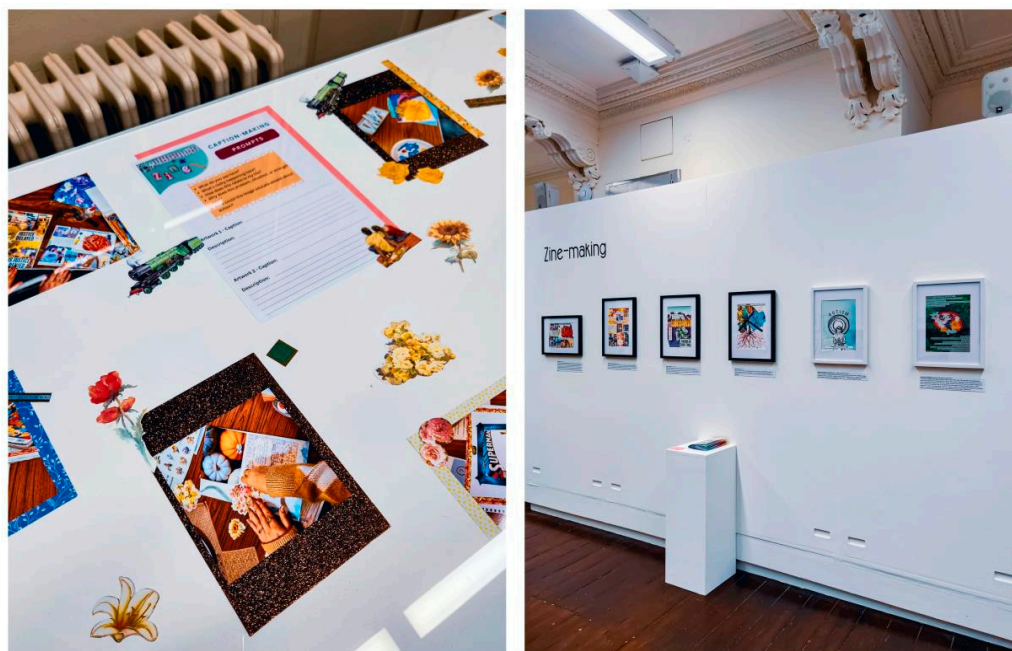


Figure 8. Picture of exhibit table displaying aspects of the zine-making process (left) and wall displaying participants’ artwork (right).

5. Discussion

In this study, two autistic women, one non-binary autistic woman, and one non-binary autistic person engaged in zine-making and group discussions about media representations of autism. This choice of population focus was driven by the fact that representations of autism have broadly operated within a male-oriented stereotype and bias [50], making it important for research to contemplate the experiences of autistic people who do not fit into this traditional stereotype. Participants produced artwork commenting on this topic, which was compiled in a ‘zine’, and spoke about experiences and impacts of representations of autism they encountered across different types of media. Some original artworks selected by participants, as well as the final printed zine containing all artwork generated in the study with self-generated captions and descriptions, were displayed in a community exhibit. Analysis of participants’ discussions and descriptions of their artwork, conducted using IPA techniques, yielded two group experiential themes (GETs).

In GET 1 ‘*No one is the same thing all the time—dehumanisation and stigmatisation in the media*’, participants discussed dehumanising and stigmatising media representations of autism. Participants emphasised that non-fictional media, including scientific papers, newspapers, and news articles, tended to portray autism as a fixed, impersonal ‘thing that is talked about’, with a focus on technicalities, as opposed to a lived experience. These monolithic accounts wiped out personhood and subjectivity, leading to objectification and framing autistic people as homogenous, abstract, juxtaposed ‘other’. This lack of nuance was also present in mainstream cinematic media, with participants discussing how most autistic characters were stereotypical, did not represent diverse experiences within the autistic population, and their subjectivity was explored in very little depth compared to

non-autistic characters. Autistic-coded characters—those who seemed autistic but were not expressly so—were reported as more relatable as their portrayal was more flexible. Participants also said that many adults portrayed in TV shows, including reality TV, were infantilised and/or denied autonomy. It was also emphasised that autistic people were very rarely portrayed as sexual, or their sexuality was portrayed in a similarly stereotypical way.

Ultimately, participants suggested that deficit-based rhetoric in science, stigmatising media representations, and negative public perception of autism were interconnected with a self-confirming bias—thus emphasising the importance of having autistic involvement in media production. Participants also commented that dehumanising media representations contributed to a delayed diagnosis because their parents/caregivers, as well as themselves, did not know what autism could look like beyond stereotypical profiles of mostly men. While research has found that consumption of TV series was linked to higher rates of self-diagnosis in autistic people [51], our participants highlighted that negative media stereotypes conversely delayed identification and/or diagnosis, both from self and others, which is a new finding. This may have arisen in this specific study due to our focus on the experiences of women and non-binary people, as autistic women are more likely to be identified late, to be misdiagnosed, or not to be diagnosed at all [22]—and because, as discussed by participants, media representations of autism are even less representative of this specific demographic.

Findings in GET 1 echo those of Fontes and Pino-Juste [52], indicating that autistic characters portrayed with exaggeration may lead to stigma. It is also in line with Orm et al.'s arguments [53], stressing that media should include more autistic actors and writers, display greater diversity, and make autism one of the traits explored in a character as opposed to their main story. Additionally, our participants' criticisms of non-fictional media portraying autism as a 'thing that is talked about', with technical and impersonal tone, align with Karamini's et al.'s [24] findings where impersonal references to autism in British newspapers were associated with more negative connotations—calling attention to the importance of humanising autism by linking it with real people and lived experiences. Participants' suggestions of a circular process between negative rhetoric in science, stereotypes in the media, and negative attitudes in society also relate to previous research where autistic people discussed stereotypes serving to justify other people's oppressive attitudes [54].

Mainstream media has the potential to promote understanding of autism, which is especially promising amongst people who may not have an academic interest or who do not directly know or relate to autistic people. However, Mittman et al. [13] found that the media types with the greatest influence and reach are also those with the greatest stigmatising effects: films and television were associated with the highest levels of stigmatisation and misinformation. Participants in the present study also described mainstream cinematic media as overall stigmatising and dehumanising, which can be particularly problematic given the high consumption rates. This is relevant given that non-autistic people tend to misjudge their level of autism knowledge, sometimes overestimating it and failing to recognise their own misconceptions [55]. Interestingly, research has found that training can be effective in shifting explicit bias against non-autistic people, but not implicit bias, which is more difficult to change as it is generated over years of exposure to negative stereotypes and therefore deeply ingrained in unconscious ways [56]. Similarly, Dickter et al. [57] demonstrated that non-autistic people may hold negative implicit attitudes but positive explicit attitudes toward autistic adults, emphasising the need for interventions aimed at reducing negative implicit bias. Given the ubiquity of mainstream cinematic media, and our (as well as previous) findings indicating the prevalent stigmatising rhetoric in it, there is a potential benefit in investigating links between exposure to mainstream cinematic

media and implicit bias against autistic people, which could also be explored as a potential locus of intervention for bias reduction.

While coded portrayals of autism (meaning portrayals where autism is not explicitly disclosed) in cinematic media may offer producers more flexibility, they may arguably have less educational value as viewers may not identify that the character is autistic, therefore being unable to shift their understanding [14]. However, our participants reported relating more to coded autistic characters than those expressly autistic due to nuance in portrayal, which is more compatible with a more neuroaffirming understanding of autism. While educational value is important for reducing stigma, our participants emphasised the positive effect of media representations that matched their lived experiences. Thus, if stakeholders in media production wish to reconcile educational value with relatedness and entertainment, a potential solution would be to make explicitly autistic characters more nuanced and less stereotypical, thereby increasing educational value for non-autistic audiences while maintaining relatability for autistic audiences. This may be accomplished by involving more autistic writers, actors, and producers in this type of media, as suggested by our participants.

In GET 2 'Figuring out what being autistic means to me—endorsing self-determined narratives', participants discussed media content that displayed humanised and/or first-person accounts of autism. These representations were found mostly on social media, or through participants' own initiative in looking for books and research authored by autistic people and/or rooted in a neurodiversity view. Participants described difficulties in constructing a personal meaning of autism amongst the prevalent negative stereotypes they had been exposed to for a long time. Thus, finding relatable accounts that matched their lived experiences had many positive effects, including fostering self-understanding, autonomy, and a sense of connectedness, and providing participants with alternative vocabulary to advocate for themselves. Participants also emphasised that humanising autism did not mean focusing only on strengths and positives—but also discussing challenges, only not in a moralising tone.

Findings in GET 2 align with those in Bury et al.'s [58] study, in which autistic participants reported learning about autism primarily from books and research, and less from TV/movies, with social media and online research positively associated with knowledge and autism identity. They also relate to Skafle et al.'s [59] findings, where autistic participants, especially women, reported missing relatable autism representation and information, which they eventually found in social media platforms. GET 2, however, also includes unique findings suggesting that media content may both contribute to internalising stigma and antidote it: our participants described that encountering humanised autism content was crucial in counteracting previously absorbed negative stereotypes prevalent in mainstream media, especially after diagnosis, allowing them to reconstruct a more personalised and less pathologized autistic identity. Moreover, participants emphasised that finding alternative portrayals of autism increased their agency and ability to advocate for themselves and communicate their needs.

Encountering humanised representations of autism in social media also fostered connectedness by decreasing a sense of dissimilarity and separation and facilitating access to support from peers. Both personal agency (e.g., making choices about one's life) and access to support are necessary for self-determination. Participants' accounts emphasised the importance of self-determined narratives of autism, and our findings suggest a potential link between exposure/access to humanised, first-person media representations and greater self-determination. This is especially important when autistic people are shown to have significantly lower levels of self-determination, with stigma being the main obstacle [60].

Taken together, the findings from our GETs emphasise the power of media in shaping both autistic people's and non-autistic people's views and attitudes towards autism, in both constructive and stigmatising ways. Our participants described a high motivation and initiative in finding accurate and relatable accounts of autism, having to transcend traditional media content that catered to, and was dominated by, neurotypical perspectives that reinforced a 'knowledge' of autism that ultimately does not match autistic people's own experiences. Participants had to look for alternative media content such as online autistic spaces and research rooted in a neurodiversity perspective, which brought greater understanding of autism and of themselves in an empowering and instrumental way. This relates to findings of a study by Gillespie-Lynch et al. [61], where autistic participants exhibited more accurate knowledge about and less stigma toward autism than non-autistic people. Conversely, non-autistic people were overall more likely to endorse stigmatising notions of autism, including the endorsement of interventions aimed at 'normalising' the autistic people to match neurotypical ideals. We echo the authors' argument that autistic people are reliable autism experts, due to their lived experience expertise and their high awareness of accurate and non-stigmatising knowledge of autism.

The use of zine-making activity and the setup of a community exhibit yielded positive impacts that also warrant discussion. For participants, zine-making fostered enjoyment and connection, with the research environment described as fun, playful, and mutually supportive. At the end of the project, in fact, some participants shared that they wished for our meetings to continue. For the wider public, the exhibit facilitated over 200 visitors accessing autistic first-person accounts and creative displays of autistic people, with both autistic and non-autistic visitors sharing that it was a pleasurable experience, that it fostered new learning and understanding, and that it made some feel represented and seen. This illustrates the unique position of cultural heritage spaces in promoting public education and engagement [62], where scientific knowledge can be adapted to wider audiences and embodied in a physical space. This is especially meaningful for research of societal relevance, as certain aspects of scientific dissemination (e.g., technical or domain-specific language) can be inaccessible to non-academic audiences and prevent knowledge from permeating wider social and cultural dialogues.

6. Strengths and Limitations

While we aimed to capture the views of autistic women and non-binary people, other intersectional autistic groups who are not traditionally represented in the media (e.g., ethnic minorities) were not contemplated in the demographics of our sample. We have also observed an acknowledged limitation in zine studies [35], where participants may lead the research in unexpected directions. The open-ended nature of zine-making meant that participants sometimes strayed from the intended focus and did not go into detail on certain relevant aspects, such as potential differences between the unique experiences of women and non-binary people, instead focusing on the shared experience of autism and stigma. Similarly, the inductive nature of this study meant that participants chose to discuss a wide range of media, which was both a strength, allowing for comparisons and contrasts across types, and a limitation, as participants did not have time to discuss each type in greater depth. The use of zine-making methodology is also both a strength and a limitation—while it favoured autistic people who enjoyed visual and artistic communication, allowing for meaningful and accessible expression, it is self-selecting, as it may exclude those who do not.

7. Conclusions and Future Directions

Our findings emphasise the importance of humanising autism by centring real people and their lived experiences in media representations, as opposed to impersonal fixed accounts that lead to stigmatisation and dehumanisation. Media production should directly involve autistic people to achieve more diverse portrayals that reflect lived realities. There may be scope for future research to explore mainstream media as a potential source and intervention locus for negative bias against autistic people, and access to first-person accounts of autism in the media as a potential facilitator for autistic self-determination. This research also highlights the feasibility of zine-making as an autism research tool and the place of community exhibits as a means of transcending traditional means of academic dissemination.

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