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Autistic people's experience of empathy and the autistic empathy deficit narrative

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Abstract

Background

There is a dominant discourse, both in clinical texts and throughout the academic literature, that autistic people lack empathy; however, over the last decade, both clinicians and academics have increasingly rejected deficit-based descriptions of autism in favour of more nuanced explanations of the experience of autistic individuals in a social world.

Methods

This study asked 76 autistic individuals about their own experience of empathy and the oft-cited empathy deficit. Data were thematically analysed and revealed a wide array of empathic self-concepts amongst respondents.

Results

Notably, there was a high proportion of hyper-empathic experiences. Many respondents reported their empathic responses to be overwhelming, or even distressing. These different experiences of empathy contrast with societal expectations of empathy, which often result in additional labour for autistic people as they navigate the non-autistic centred world.

Conclusion

Although the academic literature is, in some areas, slowly moving away from a deficit perspective, more broadly there is still a negative impact from misconceptions around autistic people and empathy. Further work needs to be done to not only explore this misconception at a societal (rather than academic) level, but to better bridge the gap around the changing ideas of empathy and real-world understanding of autistic empathy.

Community Brief

Why is this an important issue?

There is a stereotype that autistic people lack empathy, which can potentially lead to negative perceptions and biased behaviours. This stereotype has roots in earlier academic literature around autism. However, while this literature has become more nuanced over time, the stereotype persists amongst the general population.

What is the purpose of this study?

This study directly asked autistic people about their own experience of empathy and of the empathy deficit narrative in order to provide a richer description than is afforded by traditional studies that typically use questionnaire measures.

What did the researchers do?

We asked a diverse group of 76 autistic adults to tell us how they experience empathy and what their views were of the autistic empathy deficit narrative via an online survey. These data were then analysed, and themes created, using qualitative content analysis.

What were the results of the study?

The first theme, heterogeneity of empathic experiences, captured the diverse ways in which autistic people experience empathy. Some did report a lack of empathy, while others did not, and some reported experiencing extreme emotional responses (hyper-empathy). The second theme, empathy as an effortful process, captured some of the challenges experienced during the empathy process and strategies used to overcome these. The third theme, conditional empathy, captured the features of others that made it more or less likely that empathy would be experienced. Some participants found it easier to empathise with close others, animals, and other autistic people. The fourth theme, challenging the empathy deficit narrative, captured participants' perspectives on the empathy deficit narrative, which ranged from firm agreement to firm disagreement, and the perception of harm that comes from this narrative, such as interpersonal prejudice or poor clinical practice.

What do these findings add to what was already known?

Previous quantitative studies using self-report measures have found various differences in empathy between autistic and non-autistic people. This study added qualitative nuance to these findings; described diverse lived experiences of empathy amongst autistic people, particularly in relation to hyper-empathic experiences; and articulated the resistance of autistic people to the harmful stereotypes that are based on the empathy deficit narrative.

What are potential weaknesses in the study?

Due to our recruitment method, the participant sample included only those who were engaged in active online autism communities. As such, the findings here may be limited in terms of how well they capture a broad range of experiences. In addition, while an online survey allowed data collection from a relatively large number of people for a qualitative study, it also meant that, unlike more typical qualitative data collection methods, it was not possible to ask participants to elaborate or to clarify their views.

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

We hope that this study highlights the need for greater attention to the experience of empathy in autistic people. Articulation of these issues may help autistic people reflect on their own

experiences and feel “seen”. Simultaneously, education at a societal level is needed to increase awareness of these issues and reduce dehumanisation, stereotyping, and prejudice amongst non-autistic people.

Introduction

The psychological construct of empathy has a complex and somewhat elusive quality which defies easy definition.^{1,2} In part, this is because it is often defined in terms of the context within which it is being studied. For example, Eisenberg and Miller³ link it to unselfish pro social behaviour, while for Singer and Lamm,⁴ it is the ability to comprehend, or tune in to, the emotional experiences of others. These definitional differences are dissected in much detail by Bollen.⁵

Much work on empathy, particularly in relation to autism, has been done by Baron-Cohen.⁶⁻¹⁰ He suggests that empathy is both a learned skill and innately determined and provides several examples of empathy in action. These range from the motivation to sit with car crash victims, to the socio-affective check that stops one from hurting a barking dog. In his view, empathy consists of a cognitive component, an affective component, and sympathy,⁸ and more recent research¹¹ has confirmed this structure. Cognitive empathy is the ability to understand what others are thinking and feeling and is closely related to theory of mind.¹² Affective empathy is an emotional response triggered by the perception of another person's internal emotional state (emotional resonance). It is a shared emotional experience where the observer's emotional state typically mirrors that of the other person. The sympathetic response (empathic concern) consists of a motivation to alleviate suffering.

Theory of mind, or mentalisation, is the ability to make inferences about people's states of mind through verbal or behavioural information, such as facial expression, voice tones, and body movements.¹³ In the context of empathy, those inferences might relate to thoughts, intentions, and beliefs (cognitive theory of mind), or to feelings (affective theory of mind). Much research has shown that autism is associated with deficits in theory of mind,¹⁴ while further research has used this as an explanation for findings that autism is similarly associated with a lack of empathy. Specifically, more recent studies have indicated that this deficit might

be found in relation to cognitive empathy (predicated on a working theory of mind) but not affective empathy.¹⁵ In fact, a recent meta-analysis suggests that affective empathy (emotional resonance) may actually be heightened amongst autistic people.¹¹

However, various commentators have taken issue with some of the details and assumptions of this literature. For example, some of the earlier research in this area may have conflated affective and cognitive empathy,¹⁶ which made it difficult to discern what might actually be meant by an empathy deficit in autism. Similarly, while the Empathy Quotient (one of the most widely used self-report tools in this area¹⁰) has separate subscales for cognitive, affective, and behavioural components of empathy, it is more common to see analysis based on just the total score.¹⁷

Others have drawn attention to the limitations of a relatively permanent and stable trait-like conception of empathy,⁸ which much of the literature is based on. Like other traits, empathy can also be understood as a state or as a process that unfolds between individuals in specific circumstances that will vary from situation to situation.^{18,19} As a social process, empathy needs to be understood as something that happens within a context that is affected by other social processes, such as socialisation and othering. A further problem may be the confounding effect of alexithymia. Alexithymia is a difficulty in recognising and describing emotional states, which occurs relatively frequently in autistic people relative to the non-autistic population.²⁰ Controlling for alexithymia, Bird et al.²¹ and Speyer et al.²² both found no differences in empathy between the autistic and non-autistic groups in their studies, which suggests that apparent differences in empathy displayed by autistic people may be due to the co-occurrence of autism and alexithymia, rather than autism *per se*.

Further criticisms are levied by Fletcher-Watson and Bird² who regard mainstream empathy research to be laden with defective terminology, ineffective operationalisation, and poor

theorisation. This, they argue, has added to a misapprehension that autistic people lack empathy, which in turn has caused detriment to the autistic community as a whole. As an alternative, and perhaps more functional, means of investigating and defining empathy, Fletcher-Watson and Bird argue that empathy is best broken down into its socio-cognitive components and processes. For example, at an early stage, it is necessary to notice the social cues that would trigger an empathic response. Monotropism is the tendency to focus attention on single sources of information at a time²³ and has been suggested as an explanation for various cognitive and behavioural correlates of autism.²⁴ In this case, whereas polytropic processing of stimuli might allow someone to take in information from multiple sources at once, including social information that could trigger an empathic response, monotropic attention to a particular aspect of an individual's environment might reduce the likelihood that these additional social cues would be noticed.

At a later stage in an interaction, interpretation plays an important role. It can be challenging to correctly interpret social cues, and not just for autistic individuals. The double empathy problem hypothesis²⁵ suggests that autistic and non-autistic people may struggle to empathise with each other due to their very different experiences of the world. So, while non-autistic individuals have a shared understanding of the emotional, behavioural, and social cues that allow empathic understanding, their ability to make correct empathic inferences may be undermined when presented with the cues presented by an autistic person. On the other hand, empathic understanding between autistic people might be relatively unaffected.^{26,27} This is another example of how assumptions within the literature may have underestimated the empathic functioning of autistic people. Evidence that social communication within and between autistic and non-autistics adults operates in this way comes from a study by Crompton et al.²⁸ They found that information was shared equally effectively in groups of entirely autistic and entirely non-autistic participants, but less effectively in mixed groups

made up of both autistic and non-autistic participants. The mixed group also reported significantly less rapport between members.

Following observation and interpretation, there is the affective experience of empathy (a sense of affinity for the other or a resonance/mirroring of emotion) and, as already mentioned, there seems to be a growing consensus that autistic individuals show no deficit in relation to this.¹¹ Finally, this affective experience might lead to a behavioural response. In so far as that response might not align with expected (non-autistic) social norms, this is another situation where an observer might ascribe a lack of empathy to autistic people where it is actually just that empathy is being expressed differently.²

Alongside the theoretically contested and mixed empirical findings regarding empathy and autism, qualitative research has found that autistic individuals have conflicting perspectives on their own experience of empathy. For example, Russell et al.²⁹ interviewed autistic participants and found that some regretted their self-identified lack of empathy, while others noted an acute sense of empathy towards others (specifically towards others on the autism spectrum and towards animals). Similarly, Fletcher-Watson and Bird² mention several instances of autistic people describing intense hyper-empathic responses.

As yet, these experiences have not been adequately empirically investigated, though there are theoretical frameworks that explain them, such as Smith's³⁰ emotional imbalance hypothesis of autism and Markram and Markram's³¹ intense world theory. They are also in line with quantitative findings that, relative to non-autistic people, autistic people may have heightened emotional empathic responses (possibly alongside poorer performance on measures of cognitive empathy¹¹).

In an attempt to shed further light on this topic, the present research is a qualitative investigation of the lived empathic experience of autistic people. Research on empathy

typically uses quantitative methods to assess a trait-like operationalisation of empathy (e.g., via the Empathy Quotient¹⁰). However, empathy is a complex process that is highly dependent on social context. As such, a qualitative investigation may be more sensitive to aspects of the empathic experience than a quantitative one. Some commentators have suggested that the empathy deficit narrative in the research literature contributes to a process of othering and even dehumanisation of autistic people.^{2,32} Given this potential for harm to the autism community, we also wanted to recruit participants' perspectives on the existence and importance of this literature.

Method

Participants

We recruited participants via adverts posted on several UK-based Facebook groups for autistic adults. In total, 76 people contributed qualitative data that could be used as part of the data set for this study. Of these, 46 reported having a formal diagnosis of autism, while 28 were self-diagnosed (and 2 did not specify). Accepting self-diagnosed participants was felt to be appropriate as the autistic community tends to accept self-diagnosis as valid. Some autistic individuals prefer to remain ‘unlabelled’, while others can face challenges due to gender, racial, cultural, and socioeconomic reasons that prevent them from pursuing a full diagnosis.^{33,34} Additionally, research has shown that individuals who self-identify are usually accurate.^{35,36} In terms of gender, 49 were women, 18 were men, 6 were non-binary, and 3 preferred not to say. The disproportionate number of women taking part in the study, where women have traditionally been excluded from autism research, is probably partially due to the fact that participants could self-identify.³⁷ The increased representation of women in this study supports claims that self-identified autistic people should be included in research to better account for historically underrepresented experiences.³⁸

Procedure

The Facebook adverts linked through to an information sheet, consent form, and short questionnaire hosted on the Qualtrics survey platform. This contained two open-ended qualitative questions, which were: “*How do you experience empathy?*” and “*Some autism research says that people with ASD [autism spectrum disorder] lack empathy. What are your views about this?*”.* On a subsequent page, we specifically asked participants whether they

* We note that there is a broad preference within autism communities to use identity-first language and this is used throughout this manuscript. However, at the time the study was being developed it was the preference of the second author, who was responsible for assembling the questionnaire, to use person-first language. No participants reported this choice as problematic, but it may be the case that potential participants chose not to take part due to the language used.

had ever experienced hyper-empathy or extreme levels of empathy (yes/no). Following the questionnaire there was a debriefing page that contained details of autism advocacy and support groups. We did not collect any identifying information and participants could contact the researchers (referencing a code they generated) to ask for their data to be excluded from the study up to two weeks after participation. The study was granted ethical approval by the Department's student research ethics committee.

Researcher Positionality and Community Involvement Statement

This research was carried out by a White, English, autistic woman (first author); a White, Irish, non-autistic man (second author); and a White, English, autistic man (third author). Participants were autistic people who were recruited via online autism communities. The first author, who carried out this research for her dissertation on an MSc Developmental Psychology, was responsible for data collection and analysis. The second author, who is a differential psychologist, carried out further analysis. The third author sense checked the analysis. Both first and second authors come from a mainstream psychology background and have a broadly post-positivist epistemological perspective. In contrast, the third author is an academic working within critical autism studies^{39,40} with a particular interest in participatory and emancipatory approaches to research. All three authors collaborated to ensure that the values implicit in the report, and the language used throughout, align with the predominant preferences expressed by autistic communities. While there is no ideal language for all potential readers of this paper,⁴¹ we have decided to utilise identity first language as this is not only an author preference but is often cited as a preference by those who engage in research around labels.⁴²

Analysis

Responses to the two open-ended questions yielded a substantial amount of data, which we analysed using conventional qualitative content analysis in accordance with the steps outlined by Hsieh and Shannon.⁴³ We used this approach rather than, say, reflective thematic analysis⁴⁴ due to the nature of the data and the post-positivist, “small q”, perspective of the authors.⁴⁵ After initial familiarisation, we read the data and created codes for relevant and interesting content. Following this there was a refinement phase where we reviewed and integrated codes. We then graphically organised these refined codes into themes and subthemes using a thematic map (see figure 1).

Results

Four inter-related themes were created to explain participants’ responses to the questions. These were: Heterogeneity of empathic experience, Empathy as an effortful process, Conditional empathy, and Challenging the autism deficit narrative. Particularly important subthemes were also identified, which are discussed as part of a continuous narrative within each theme, below.

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Heterogeneity of empathic experience

This theme refers to the diverse quality of empathic experiences that participants reported having. The main subthemes within this included a self-perceived *lack of empathy*, experiences of *hyper-empathy*, and related *distress and dysfunction*.

Of course, autistic people are not a homogeneous group when it comes to empathy. Some expressed uncertainty (“*I’m not sure*”) or reflected on the difficulty of characterising a trait

that is fundamentally relative in nature (*"I'm not sure, compared to other people, because I've never experienced anyone else's brain or psyche"*). However, many articulated quite clear positions as to their own experience of empathy or the experience of autistic people in general. Of those, some reported experiencing a lack of empathy in accordance with the dominant empathy deficit narrative (*"Personally, I do feel I lack empathy"*; *"I don't often feel like I empathize with other people"*; *"We can't understand what people are thinking/feeling"*). Others reported no such lack, but suggested that their empathy might not be apparent to others. They might experience a difficulty in knowing how to express an empathic response (*"I believe I have a great deal of empathy, but the issue is in understanding and expressing it"*) or their expression might not accord with non-autistic norms (*"We tend not to display our empathy outwardly in ways that neurotypicals tend to expect"*; *"We don't lack empathy, we just show it differently"*). Some went further and questioned the validity of non-autistic empathic responses (*"I also think there is less false empathy"*; *"I wonder if maybe autistic individuals feel the same empathy as others but are more likely not to pretend to feel it like allistic [non-autistic] people might?"*). In other words, it is not that autistic people have a lack of empathy, but that non-autistic people have a demonstrative surfeit (*"we lack performative empathy"* as one participant puts it).

In contrast to those who reported a lack of empathy, many participants characterised their empathic experience as a normative one (*"I get excited when others around me get excited. I cry when my family cries"*; *"I do not seem to have a deficit"*), while one participant described a synaesthetic empathic response (*"I can feel or 'see' other people's emotions. Someone will appear as though they are under a colored light"*). However, a majority of participants reported experiencing hyper-empathy and extreme empathic responses. Seventy eight percent of participants responded yes to the yes/no question about whether they had ever experienced hyper-empathy or extreme levels of empathy. This also came through clearly in

the qualitative comments. Whereas participants who reported experiencing a lack of empathy might have referred to *understanding* thoughts and feelings (i.e., cognitive empathy), those who reported a surfeit of empathy were more typically speaking of emotional resonance or affective empathy. For example, *“I have experienced overwhelming empathy most of my life”*; *“Some people on the spectrum are incredibly empathetic, almost to a fault”*; *“I absorb other people’s emotions, and I almost know how people are feeling before they are aware of it themselves”*.

While one participant framed her empathy in positive terms (*“I consider empathy my superpower”*), most used relatively negative language. Many talked about feeling overwhelmed (*“It is like a huge wave of emotion that sweeps me off my feet”*; *“It is emotionally overpowering”*; *“I often feel overwhelmed with anger/grief/happiness on behalf of other people”*) and experiencing an emotional response that is so powerful and uncontrollable that it causes distress (*“[It is a] deep sad feeling”*; *“It feels crushing”*; *“It is overwhelming, makes me feel anxious”*). Often, this sense of distress was somatised as participants described it in terms of pain or other physical manifestation (*“I feel nauseous”*; *“I feel empathy so much that it’s painful”*; *“I feel physical pain in my body”*; *“I feel a horrible sensation in my body like my innards are being twisted”*). Participants also reported negative consequences of this distress (*“It is all encompassing and can be debilitating”*; *“I get a surging emotion from deep inside that renders speech difficult”*; *“It makes my knees feel as if they are about to buckle”*), most commonly in terms of a withdrawal response (*“Sometimes I get overwhelmed and shut down”*; *“[I] find it hard to deal with, which causes me to shutdown”*). This “shutting down” is a functional (avoidant) coping response to an aversive emotional state, but one participant reported a more long-term and adaptive coping journey: *“With anti-depressants and years of therapy I now can cope with most of my empathy.”*

Empathy as an effortful process

This theme refers to the additional labour that some autistic people need to do to engage empathically with others. The main subthemes within this included *difficulty in the detection of emotional cues*, the idea that *empathy is a skill that can be developed*, and the *purposeful effort* that empathy requires.

As a response to the emotions of others, empathy must necessarily be preceded by awareness of those emotions. Some participants suggested that they were only aware of such emotional cues if they were particularly obvious (“*I also will miss others emotions at times, not realizing they are angry, bored, or otherwise if they are passive or subtle with me*”; “*I like obvious TV where you know to empathise*”; “*I wouldn’t be able to pick it up myself unless it was obvious like they were crying*”), though one participant framed this as a disjunction between autistic and non-autistic modes of expression (“*autistic people may not easily pick up on the unwritten social cues of neurotypical people*”) rather than as something intrinsic to autistic people. To deal with this difficulty, some autistic people might develop compensatory practices. Several participants described a purposeful, reflective, process of attending to others’ emotional state (“*I try to be hyperaware of other people’s boundaries*”; “*I make a conscious effort to try and see the world from other’s perspective*”; “[*empathic behaviour is easier*] if one has the cognitive capacity to compensate by hyper-awareness of subtle cues in other people”), though this effort takes a toll (“*it’s exhausting and sometimes I just stop interacting all together*”).

Participants also suggested that it takes work to become empathic – that it is something that one learns over time (“*If one is raised in the right environment and puts forward continuous effort the ability to feel empathy is a skill that can be learnt*”; “*we can learn empathy from others and education*”) or that develops with age (“*[I] have grown more empathetic with age*”).

and life experience”). One participant suggested that whether empathy is learnt or not might also be a function of gendering (“*I feel autistic women/girls learn empathy very early on*”).

Conditional empathy

When asked how they experience empathy, several participants said, “*it depends*”. This theme covers some of the factors upon which participants’ empathic responses were dependent. The main subthemes included empathising with *close others*, empathising with *animals*, and empathising with *autistic others*.

Many participants suggested that they were particularly likely to feel empathy for family members and close others (“*[I experience empathy] only for a short time for someone close to me. Otherwise not at all*”; “*It is more intense with people closest to me*”), though one participant indicated the opposite (“*I am much more likely to empathise with a stranger sometimes than people close to me where I can’t see the wood for the trees sometimes because I’m too involved. It’s easier to be objective*”).

One participant included animals in this group of close others (“*I feel sympathetic and sad when my friends have problems and have very strong feelings when this applies to family and my animals who are also family*”), but empathy for animals was actually experienced much more broadly than this. Many participants specifically noted empathy for animals (sometimes in contrast to a lack of empathy for humans) in their answers (“*I feel empathy on some occasions, to people close to me. I’ve more feelings towards animals*”; “*I really only feel it for animals particularly dogs. I can’t bear seeing animals suffer*”).

As mentioned above, mismatch between the social cues used by autistic and non-autistic people can hinder the ability of autistic people to detect potentially empathy triggering cues displayed by non-autistic people. In line with this, many participants also reported finding it

easier to experience empathy in relation to other autistic people than non-autistic people. For example, one participant wrote, *“I find it easier to empathise with other neurodiverse people as they tend to react more similarly to myself. With some people in society our reactions are so different [...] that we don’t seem to relate to each other at all”*, while another wrote, *“the less like me they are, the less accurate my suppositions [about their emotional state] are”*.

Another participant wrote at length on this same theme and explicitly contrasted the “difference” and “deficit” models of autism:

“It can be more difficult to innately empathize with 'neurotypical' people [...] their minds experience things differently thus how they are feeling, what they're thinking, or what their intentions and motivations are will be more alien as compared to those of an autistic mind. [...] However, the very same has happened with roles reversed, with 'neurotypicals' acting callous toward me when I'm upset by something they think is trivial. It goes both ways, honestly, and has nothing to do with an absolute lack of empathy and a lot to do with differences in how minds experience things. [...] the majority of 'deficits' in autism are simply differences [...]. I get along perfectly well with my autistic friends and there is no lack of empathy nor intimacy between us.”

Challenging the empathy deficit narrative

This theme encompasses people’s reflections on the empathy deficit narrative and on autism and empathy research in general. The main subthemes within this included the *lack of consensus* as to whether the narrative is accurate or not and the perception that the narrative may *potentially be harmful*.

First, it was clear that this strand of research is a highly emotive issue for some autistic people: *“[It is] outrageous bullshit that brings into question the validity of autism research*

completely". That said, whether people agreed or not with the idea of an empathy deficit was as varied as their own experiences of empathy. These views ranged from outright dismissal ("*It's complete nonsense*"), to nuanced disagreement ("*It seems like a misunderstanding to me*"), to nuanced agreement ("*I don't think it's true for everyone with ASD*"; "*I tend to agree with this to an extent*"), to firm agreement ("*I agree*"; "*It rings true for me*"). Many who disagreed with the idea of an empathy deficit pointed to their experience of hyper-empathy ("*This is untrue. In my experience we are far more empathetic*"; "*I feel quite the opposite, I am over empathetic for sure*").

There was also an awareness of the potentially harmful effect the empathy deficit narrative has on the autism community, either in terms of stereotyping in the general population ("*The general public believe it and it is a direct cause of prejudice and othering*") or in terms of professional practice ("*I think it is a stereotype which causes a great deal of harm and I am especially upset when I hear trained psychologists assume a person cannot be autistic because they have empathy*").

Discussion

This study aimed to explore both autistic experiences of empathy and the response of autistic people to the empathy deficit narrative using qualitative analysis. The main finding is that the autistic experience of empathy is complex. In contrast to a simple deficit narrative, most participants rejected the idea that autistic people lacked empathy, and many reported experiences of hyper-empathy. In total, 78% of participants indicated having experienced hyper-empathy (yes/no question) and this was reflected across many of the qualitative comments.

This finding may align with quantitative findings that autistic people have, on average, a heightened affective empathic response relative to non-autistic people.¹¹ Experiences of hyper-empathy are common anecdotally amongst the autism community,² and have been picked up tangentially across the academic literature.⁴⁶ As yet, however, there has been limited theoretical and empirical work looking at this as a specific phenomenon worthy of study in its own right.³¹ The predictive processing account of autism, which suggests that autistic people tend to be more attuned to new sensory information that deviates from predictable patterns, may be useful here.⁴⁷ Empathy-triggering social cues undermine environmental predictability, and might add further predictive uncertainty if one has to consider the potential consequences of one's own behavioural response to those cues. As such, they may lead to sensory overload and a heightened, potentially aversive, emotional reaction. Outside of the autism literature, Leonard and Willig⁴⁸ have thoroughly dissected the functional consequences of hyper-empathy, which can be either beneficial or maladaptive.

While there is a broad trend across autism communities to reject pathologising and deficit-based frameworks,⁴⁹ some participants did report struggling with various components of the empathic experience, including, as frequently reported in the literature, the cognitive aspects of empathy.¹¹ In providing space for autistic people to express their own thoughts and experiences there must be recognition that there will be a diversity of views,⁵⁰ as is reflected in these findings, and that these views are valid reflections of an individual's experience. If not, we fall into the problematic practice of invalidating autistic experiences that has been seen in traditional research.⁴⁹

As described in the introduction, empathy can be thought of as a process of detection, interpretation (i.e., cognitive empathy), emotional resonance (i.e., affective empathy), and sympathetic concern, which may trigger a behavioural response. All of these were referred to in participant responses that described difficulties with empathy. Participants reported having

to be extra-vigilant to detect empathy-related cues; having difficulty in interpreting those cues, especially where subtle or where produced by non-autistic people; and being perceived as reserved in their sympathetic response. Participants also reported that actively engaging in these processes takes a psychological toll, which might cause them to consciously opt-out of effortful empathising. That said, it may be more appropriate to trace some of these experiences to trait alexithymia rather than autism, given the recognised overlap between the two.²⁰

It was also clear that, whether cognitive or affective, participants' experience of empathy was contingent. Many participants couched their responses tentatively (e.g., "it depends..."), while it was also common for participants to explicitly state that they were more likely to experience empathy in relation to close others, animals, and other autistic people. As with hyper-empathy, there has been some prior indication in the academic literature of these contingent empathic responses.²⁹ Of course, it is well known that there is an in-group bias for empathy,⁵¹ but the experience of empathising more readily with other autistic people could be taken as support for Milton's²⁵ double empathy problem hypothesis. The other side of the double empathy problem coin – that difficulties arise due to interpersonal mismatch and are as likely to be experienced by non-autistic people in relation to their empathic response to autistic people – was also articulated by participants. This phenomenon was also observed in another recent qualitative study⁵² that discussed findings from interviews with autistic people about their relationships with others.

It was also striking how difficult participants' relationship with empathy is. Outside of autism, narratives around empathy are almost universally positive. It is a desirable trait that underpins successful interpersonal functioning.⁵³ Here, however, while one participant framed her empathy in positive terms, most used relatively negative language. People talked about being overwhelmed and distressed, becoming burnt out, and shutting down. People

talked about the additional labour that needs to be done to make the right kind of empathic inferences and responses (a form of social camouflaging⁵⁴). The way in which participants couched their empathic response in somatic terms was particularly striking, and has not, as far as we are aware, been described outside of narrative accounts previously. This is likely to be a specific manifestation of the broader hyper-empathic response that participants reported and is another way in which the autistic experience of empathy can be a negative one.

Participants were clearly aware of research in this area and were comfortable using phrases and concepts from the academic literature in their responses ('cognitive empathy', 'affective empathy', 'alexithymia', etc.). Empathy is perceived to be central to the network of concepts surrounding autism, so it is to be expected that autistic people would make themselves familiar with empathy-related research. For some, this will simply be about gaining a greater understanding of themselves, which might lead to their self-concept aligning with the empathy deficit narrative. For others, it could be part of a conscious effort to overcome hermeneutical injustice⁵⁵ and challenge stereotypes. There is certainly evidence for the latter within the current study, as some participants spoke powerfully about their perception of the empathy deficit narrative within the literature as inaccurate and about the harm that it can have on the autistic community more generally.²

Limitations and Future Directions

The current study provides valuable additional insight into the empathic experience of autistic people. Most previous work on this topic of autism and empathy has been quantitative in nature, while accounts of autistic people's lived empathic experience have been, for the most part, anecdotal. The method of data collection, via an online survey, was a strength in that it allowed data from a large number of autistic people to be collected. On the other hand, one of the strengths of using interviews to collect data is the ability to ask probing questions that allow participants to elaborate on what they have said. This was not possible here. Future

work should seek to extend the findings from this study using interview methods. The sampling method, via active online autism communities, represents another potential limitation in so far as it might restrict how well the study was able to capture a broad range of autistic experiences. The demographic data we collected was limited, and did not include age, nationality, or ethnicity, so it is difficult to get a sense of just how broad the sample was. In relation to gender, the fact that most participants were women potentially undermines the representativeness of the sample in relation to the overall autism population (where men are more common).

Gender may be particularly important to consider as it is a powerful predictor of self-reported empathy.⁵⁶ Simultaneously, autism is a much more common diagnosis within men than women.^{57,58} Thus, future research looking at autism and empathy, should consider the degree to which gender might act as a confounding variable. It's also been shown that the gap in self-report empathy between *autistic* men and women is narrower than that between *non-autistic* men and women.¹⁷ This could be due to a possible interaction between autism- and gender-development processes (e.g., socialisation) on empathy, or it could be a consequence of the gender-bias in the (androcentric) diagnostic criteria for autism.⁵⁹ For example, women may only be diagnosed as autistic if they fit the stereotypically masculine low empathy profile.

Given the position of empathy as a gender stereotype, autistic men and women may also differ in the degree to which empathy intersects with their masking behaviour, wherein individuals effortfully adapt to predominant social norms.⁶⁰ On the one hand, autistic people are all too aware that they are supposed to suffer an empathy deficit,² which may lead them to respond in line with this identity in studies. On the other hand, women are aware that they are supposed to be empathic.⁵⁶ This all becomes more complex when one considers that gender is a non-binary construct. Studies in this area often limit themselves to looking at just men and

women, but this means that people with non-binary gender identities are not being represented in the literature. For example, the large-scale study by Greenberg et al.¹⁷ excluded over 20,000 people who did not identify as male or female. This is particularly problematic in studies looking at autism, as autism seems to be associated with a greater preponderance of non-binary gender identities.⁶¹⁻⁶³ In sum, future discussion of autism and empathy should also consider the possible role of gender, including non-binary gender identities.

The hyper-empathy reported by most participants also needs to be studied in more depth, particularly the degree to which somatisation occurs across autistic people. The development of a purposefully created hyper-empathy questionnaire would be helpful for this and would also permit straightforward comparisons between autistic and non-autistic populations.

Conclusion

This study has shown that the autistic experience of empathy is much more complex than suggested by the empathy deficit narrative. The study is particularly valuable in that it provides an autistic and qualitative perspective on empathy, whereas most previous work on empathy has been quantitative, and previous work on the subjective experience of autistic people has not looked specifically at empathy. A key finding is the recurrent presence of hyper-empathy and the way in which that was characterised by participants.

The academic literature continues to add nuance and detail to what is known on this topic, and it is clear from this literature that a simple overarching deficit explanation is not tenable. However, it was also clear that many participants continue to struggle either with their experience of empathy, or with the socially dominant notion that autistic people lack empathy. We hope that this study's findings help autistic people to better reflect on their own empathic capacity and empathic experiences. Accuracy of public awareness about autism is a

key priority for autistic people⁶⁴ and we also hope that our findings are useful in this regard. In so far as simplistic and inaccurate ideas about empathy may well underlie the dehumanisation of autistic people,² it is essential to expand the conception of what autistic people are like beyond these widely held stereotypes.

Authorship Confirmation Statement

L.K. and D.V. contributed to the conception of this study. L.K. contributed data for analysis. L.K. and D.V. conducted data analysis. All authors conducted interpretation of results, revised the article, and approved of the final version for publication. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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Figure Legends

FIG. 1. Structure of themes and subthemes.