Chapter 18:

‘I couldn't describe to you this pain that I've lived with for so long’: How the Double Empathy Problem and Hermeneutical Injustices Contribute to Autistic Adults’ Disparate Health care Access

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Introduction

The Double Empathy Problem is increasingly recognized within health care literature as contributing to autistic adults’ poor health care access and health outcomes (e.g. Strömberg et al., 2021; Weir et al., 2022). Coined by Dr. Damian Milton to refute the assumptions of proponents of deficit models of autism, such as autistic people lacking a theory of mind (e.g. Happé, 1993), the Double Empathy Problem occurs when interactions between people with different life experiences and “ways of being” (Milton et al., 2022) – such as autistic and non-autistic people – break down due to a lack of mutual understanding and reciprocity. The non-autistic social majority perceives this as a ‘breach’ of social norms (Milton, 2012). Within health care, the Double Empathy Problem can contribute to autistic patients not having their health care needs met as they do not ‘perform’ illness (see Hillman, 2014 for an account of the performance of illness) as expected (Ali et al., 2022; Strömberg et al., 2021), which is then perceived as a ‘breach’ of the social norms of patient behaviour.

Despite the increasing recognition of the Double Empathy Problem within health care research, the medical model – in which a person with neurological differences and/or physical impairments is seen as inherently disabled and in need of treatment or curing – prevails. Under the medical model, the fault for breakdowns in communication is situated within autistic people. Autistic people are deemed as having an inherent communication ‘deficit’ or ‘disorder’, which is often cited as the cause of a lack of reciprocity between autistic and non-autistic communicators (Araujo et al., 2022). Of particular importance to health care communication, some researchers consider autistic people as inherently lacking the ability to determine what information is relevant in conversations (e.g. Papp, 2006). These views construct and reproduce a compulsory communicative normalcy, with those who do not meet it being deemed deviant or in breach of social norms.

Outside of the autism literature, researchers studying communication between health care practitioners and their patients have found breakdowns in relevance and understanding. However, rather than situating this breakdown as a communication deficit within patients, there is recognition that the differing lifeworlds of health care practitioners and their patients – or even between health care practitioners from different clinical specialities – leads to a mismatch in cultural competence and the resulting misunderstanding (e.g. Batten et al., 2019). This mirrors empirical research into the Double Empathy Problem between autistic and non-autistic conversation pairs, which also uses relevance theory to conclude that the breakdown in understanding is mutual and no party is more at 'fault' than the other (G. L. Williams et al., 2021).

The increased use of the Double Empathy Problem in research and practice has also seen an increase in its tenets being misused or misunderstood. For instance, a recent study into communication between autistic teenagers and their health care practitioners referenced the Double Empathy Problem while situating "challenges in social connection" within the autistic participants (Araujo et al., 2022). The irony of this contributory hermeneutical injustice (Catala et al., 2021) – more on this later – is that the Double Empathy Problem is likely to be partially a result of hermeneutical injustices. This form of epistemic injustice occurs when a speaker (here an autistic person) is disadvantaged or unable to make sense of their experiences in a way that either harms or wrongs them due to a lack of terms or concepts (Annesley, 2020; Carel & Kidd, 2014; Fricker, 2007; Pohlhaus, Jr., 2019). The non-autistic social majority construct and uphold the communicative normalcy and neuronormativity that lead to perceived social 'breaches' through acts of "willful hermeneutical ignorance" (Pohlhaus, Jr., 2019, p. 17) in which there is little attempt to acknowledge that there are different ways of experiencing the world or, where it is acknowledged, dismissing or ignoring these differences.

In this chapter, I use data from my study into the telehealth experiences of autistic people to explore instances of the Double Empathy Problem that are problematized within autistic patients to see how they affect medical encounters. I particularly focus on my autistic participants' stories of inability to describe symptoms, pain, and emotions. Rather than the idea that autistic adults essentially cannot describe these embodied sensations, I consider that autistic adults might struggle to describe these sensations because non-autistic people's experiences inform the ways things like pain and emotions are conceptualised – both the words used and the expected 'performance' of these experiences. These could be considered examples of hermeneutical injustice. I employ instances of my autistic participants being disbelieved by their health care practitioner (known as testimonial injustice) within their accounts and discuss how these could lead to autistic adults being excluded from contributing to the collective meaning-making which enables shared understanding, known as societal hermeneutical resources, which I believe to be a key contributor to the Double Empathy Problem. If autistic people were enabled to contribute to society's collective hermeneutical resources, there is likely to be an increase in mutual reciprocity and empathy, potentially reducing instances of the Double Empathy Problem.

Methods

The data for this chapter were collected during the summer of 2022 as part of my master's research regarding autistic adults' experiences of ableism during their telehealth appointments. The project received ethical approval from Cardiff University's Social Science Research Ethics Committee, study reference 131. A recruitment advertisement was shared on social media for autistic adults (18+) to self-refer to the study if they had received an appointment using telehealth – health care by telephone or video call – in the United Kingdom within the past five years. As there is little difference in presentation or research responses, autistic adults could be formally or self-diagnosed and no diagnostic paperwork was requested as ‘proof’ of diagnosis (Brice et al., 2021; Schalk, 2017).

Participant-facing information included Easy Read versions that were sent to all potential participants without the need for participants to request these. Documents were produced on pale yellow backgrounds to mitigate the visual processing difficulties some autistic people have, as suggested by members of the autistic community who were consulted during the project’s conceptualization and design stages. I utilized a three-stage consent process (written consent by pdf or online using Qualtrics, the participant telling me in their own words their understanding of what they were consenting to at the start of each interview, followed by a verbal – spoken or typed – confirmation that they were happy to proceed) to avoid the infantilizing automatic exclusion of autistic people with a co-occurring learning disability. Ten participants completed the consent process and were interviewed by a mode of their choice, either video call (n=8), synchronous Zoom text chat (n=1), or email (n=1). Participants were given a colour-coded copy of the interview guide in advance to prepare what they might like to discuss during interviews. Most participants were White British, with one Pakistani, one Latino, one Mixed White, and one White non-British participant. Ages ranged from 26 to 61, with a mean age of 41. Participants spanned the gender spectrum, with four cisgender women, three non-binary people, one transgender woman, one gender-fluid person, and one cisgender man. While all participants primarily discussed their experiences as autistic patients, two participants also consented to be identified in write-ups as health care practitioners. Their accounts give additional perspectives on the difficulties faced during (tele)health care interactions.

Interviews were transcribed and pseudonymised immediately after ending. Participants could choose their pseudonyms to balance the erasure of autistic identity within research literature with the need for anonymity. Data were analysed using Braun and Clarke’s (2022) six-phase reflexive thematic analysis:

1. Familiarisation through multiple readings of the transcripts, making notes of initial thoughts in the margins, and memo writing.

2. Coding, initially using an experiential semantic approach with later coding rounds using a latent, critical approach focusing on how my participants talked about their health care experiences.
3. Generating initial themes and cross-checking them across the dataset.
4. Developing themes, combining similar initial themes, and recoding transcripts where themes needed further development.
5. Naming themes to ensure they captured the meaning of each theme.
6. Writing up while maintaining reflexivity and theme construction throughout the writing period.

This chapter focuses on instances of the Double Empathy Problem and epistemic injustices within the original analysis. Before writing this chapter, a further round of deductive coding was undertaken to ensure no missing items and that instances of the Double Empathy Problem and epistemic injustices were found across the dataset. A write-up of the full data analysis can be found in my master's dissertation (see K. Williams, 2022).

The Double Empathy Problem

The difficulties Batten (2019) described in the communication between health care practitioners and their patients have been considered by autistic clinician-researchers, who have theorised that this mismatch of relevance and understanding is another example of the Double Empathy Problem (Shaw et al., 2023), and is something that health care practitioners are aware of and seek to mitigate. Christina, one of the study participants who is also a health care practitioner, provided an account of how they are mindful of potential breakdowns in understanding between health care practitioners and patients, regardless of neurotype:

> "[W]hat a patient understands can be very, very different to what the doctor thinks they understand, and it's really important to keep that in mind on both aspects. And for that reason, a lot of the time, you know, you may call in a patient for a face-to-face just to make sure that they've understood properly, and I've definitely had patients not understand."

However, this difficulty seems to be more common in communication between autistic patients and (presumed to be) non-autistic health care practitioners. Drs Doherty and Shaw have described this as the triple empathy problem (Shaw et al., 2023). Furthermore, rather than acknowledging that breakdowns are a result of differing cultural competencies (as with non-autistic patients), the breakdown in communication is perceived and talked about as a breach, such as in Daisy's account:

> "And so I've tried to speak in their language and say, 'Oh yeah, take my blood pressure at home. I do have a home blood pressure monitor, but I get stressed when I'm doing it, so it probably doesn't get a good reading, so I'm better to come to the surgery to have my blood pressure done.' But that comes across as I don't like doing it, so I don't know why they wrote I don't like doing it, I thought I got the language just right. To make it sound as if I spoke their language. But that was frustrating."

Daisy described how she felt that she spoke a "different language" to her health care practitioner and how she tried to "speak in their language". Despite this extra cognitive burden taken on by the autistic participant, Daisy's account of her neurotypical health care practitioner's interpretation of their interaction was that Daisy just "[didn't] like" taking her own blood pressure at home, and this was written as 'fact' into Daisy's medical file.

Despite the Double Empathy Problem being theorised within the autism literature, breakdowns in mutual understanding based on cultural competencies that are perceived as 'breaches' in social norms by the members of the dominant social group can also be found outside of differences in neurotype. For instance, Scragger's account reminds us that the Double Empathy Problem can be experienced between any two (or more) people with differing dispositions, such as those with different ethnic or cultural backgrounds:

> "Yeah, cause if in [European country] if I was crying and a doctor went like this <opens arms wide>, they were, you know I'd give them a hug. They were gonna make me feel better. Here, I did that, and oh my God! Was that the wrong move! The looks I got of, 'What the hell are you doing? Get out of this room!' You know, so that, not knowing how to react to people and trying to, you know, fit in and do the right

> thing, it all just, I suddenly became incapable of knowing how to act in a doctor surgery and then that anxiety just means I'm at my worst."

That said, the specificity of difficulties arising with mutual understanding due to conversation partners being cross-neurotype was highlighted in Sarah's account of trying to describe her pain to health care practitioners, in which she thought that I – an autistic non-health care practitioner – would "get more idea" about her pain than a non-autistic health care practitioner:

> "I couldn't describe to you this pain that I've lived with for so long now, I wouldn't be able to describe it to you properly. Whereas I suppose I, actually, cause you're autistic, you would probably get more idea than a non-autistic person."

Sarah suggests that as we are both autistic, there would be no breakdown in mutual understanding if she described her pain to me. There would be no 'breach' of 'norms' in her performance or testimony of her pain with an autistic conversation partner. This is likely due to our shared cultural competencies and, therefore, sharing hermeneutical resources regarding autistic expression of pain and ways of being, including how we talk about our experiences. Therefore, I suggest that the Double Empathy Problem is closely linked to epistemic injustice, in which people who belong to a minoritized group's "capacity as knowers" (Pohlhaus, Jr., 2019, p. 16) are harmed either due to being seen as unreliable knowledge producers (testimonial injustice) or – more relevant to the Double Empathy Problem – by not having the social or cognitive resources to be able to talk about their experiences in a way that is understandable by the social majority (hermeneutical injustice). The rest of the chapter focuses on how the participants' accounts provide examples of where they have been subjected to epistemic injustices. I later return to the Double Empathy Problem to discuss how both it and epistemic injustices are mutually constructed and upheld in a society designed around neuronormativity.

Testimonial injustice

Testimonial injustices occur when a person's knowledge is unduly deemed to be inaccurate or unreliable in a way that harms them due to them belonging to a minoritized group (Fricker, 2007). For instance, autistic people are often subjected to a sub-set of testimonial injustice known as preemptive testimonial injustice, in which it is assumed that autistic people are inherently incapable of correctly describing their experiences *because* they are autistic, and instead, their parent/carers are engaged with as epistemically more valid knowers (Catala et al., 2021). More commonly discussed, however, are systematic testimonial injustices in which the hearer dismisses a speaker's testimony. While this is often considered to occur at an individual level, systematic testimonial injustices can be structural when 'common-sense' theories of experience – e.g., due to institutions being structured around neuronormativity – mean that it is standard to dismiss the first-person testimony of people from minoritized groups, e.g., autistic people (Catala et al., 2021).

Within health care, women are often subjected to systematic testimonial injustice, for example, having their symptoms of heart attack being dismissed as a less serious condition (such as anxiety) due to their a-typical presentation, despite health care practitioners being aware of these a-typical presentations appearing more frequently in female patients (Annesley, 2020). For autistic patients, I consider that the Double Empathy Problem and the pathologizing of autistic communication leads to testimonial injustices when autistic patients are communicating with their non-autistic health care practitioners.

In the following example, ACP16 gives an account of their health care practitioner not believing they are autistic:

> "[H]e demanded to know why I wanted a [specific] referral. Not asked, not enquired, demanded. I explained that I'd already written out in detail in the online application (which he clearly hadn't read. And he told me to explain anyway) so I pointed out 40% of autistic people have [other neurodivergence], to which he retorted, 'Why do you think you have autism?' Uhh… because I'm autistic? I was diagnosed a few years back? Apparently that information was not on my records,

> and he told me to upload evidence – but he didn't know how to do that – so I had to take a copy of my NHS diagnostics paperwork into the surgery for them to scan on."

ACP16's account is interpretable as an example of their health care practitioner deeming them untrustworthy. Indeed, the burden of proving that they are autistic fell on them, despite having an National Health Service (NHS) diagnosis. This extra labour resulting from being or feeling disbelieved is something that Pohlhaus, Jr., has termed "epistemic agential injustice" (Pohlhaus, Jr., 2019, p. 21). Furthermore, their account provides an example of their health care practitioner not being reciprocal with their language around autism, as ACP16's use of "autistic" is responded to by their health care practitioner with "have autism". This is hearable as a deployment of neurotypical power to construct appropriate communication and vocabulary, while being a manifest example of the Double Empathy Problem as the health care practitioner fails to relate to or empathize with his autistic patient. Furthermore, this experience is not unusual. Sarah describes how her health care practitioner dismissed her pain and other medical symptoms and failed to empathize with her needs by deploying the autistic characteristic of Sarah having sensory processing differences as a reason to reject her testimony:

> "This doctor said, 'You're imagining your pain, and I think what you need to do is go back to your GP and ask for some antidepressants, and the antidepressants will help suppress all the sensory issues that you are experiencing.'"

These instances of testimonial injustice, together with the Double Empathy Problem, can lead to what is known as testimonial smothering, in which a person whose testimony has been dismissed or inappropriately deemed uncredible due to bias stops engaging with the person or structures that have dismissed them (Catala et al., 2021). For instance, Josie described why she seeks private health care where possible due to being "too weird" for NHS services:

> "I'm always very sceptical that standard health care will actually be able to help quite often. Because so much of my experience has been like, 'Oh, you're too weird for us to know what to do,' or 'Oh, that's

> not actually a real problem. You're just imagining it.' Like so much of it has just been like, 'We provide health care for these things, and you're just not that.'"

Furthermore, testimonial injustices – including testimonial smothering – can lead to hermeneutical injustices, as those who are deemed credible (in relation to this chapter, non-autistic health care practitioners) are those who create hermeneutical resources. That is, the collective social resources used to determine understanding and meaning (Catala et al., 2021). In the case of my participants, the dismissal of their lived experience of their health care needs (testimonial injustice) results in a lack of words or concepts for them to be able to describe their experiences in the future effectively and for their 'performance' of illness being misunderstood (hermeneutical injustice), and for a mutual difficulty in empathy and understanding (Double Empathy Problem).

Hermeneutical injustice

Without dismissing the intrinsic difficulties some autistic people might have describing how they feel, such as those who have alexithymia (Cassidy et al., 2014; Moseley et al., 2020), I consider that for many autistic people, their struggle to describe bodily sensations might be due to non-autistic people's experiences creating the ways in which pain and emotions are conceptualised – both the words used and the expected 'performance' of these experiences. When all conversation members share hermeneutical resources – such as Christina and Daisy due to them being health care practitioners and autistic patients – there are likely to be fewer communication breakdowns. As Daisy says in her interview, "I'm a [health care practitioner] too, which helps as I already know how it works, and I can ask for what I need."

Christina's account provides an example of how important shared hermeneutical resources are, especially when considering the different ways vocabulary can be understood in different cultural contexts:

> "[B]eing medically literate is very helpful because I know the terms to use, whereas other patients will use words that don't have the same meaning in lay terms like 'tender' is a good one, or 'fever'. What

> people interpret it as, and what fever mean, and feeling feverish and things like that."

In practice, hermeneutical resources are taken for granted as being intrinsically part of human experience and knowledge rather than acknowledged as being socially constructed. The rapid shift to telehealth during the COVID-19 pandemic reveals how the act of describing medical symptoms is not a straightforward, common-sense act but rather is mutually and situationally negotiated and relies on all parties having access to mutually understandable concepts and vocabulary:

> "It was, yeah, trying to explain things and describe things and explain what your [body part] looks like over the phone. And how exercises hurt, cos usually obviously you go to [joint care] you'll usually say, 'Oh, when I put a [body part] like this, it kind of hurts.' But trying to verbalise that over the phone was difficult. Yeah, trying to explain what the [symptoms] that particularly hurt your [body part]. So you just try to find like terms to describe things like [symptoms]. And just hope that they know what you're talking about"
>
> (Amy)

Amy's extract demonstrates how hermeneutical resources are based on cultural norms. The resources drawn upon to describe joint pain rely on the (previous) cultural norm of in-person health care. Therefore, telehealth revealed a gap in hermeneutical resources: how to describe something you would usually physically demonstrate in an understandable way. The 'typical' way of expressing herself (physically showing the health care practitioner what was wrong with the joint) was impossible. Instead, Amy had to try to find "terms" to describe something she would typically show, putting her and her health care practitioner at a disadvantage and reducing the efficacy of her health care.

Lyla describes a similar difficulty with telehealth:

> "I don't feel like they were real doctor's appointments cause I was just like talking to someone on the phone, especially if they needed to actually check me physically, or look for something. There's only so much I can do with talking words to describe what – at some point

> when you're in the room, they get the stethoscope out or, you know, check something or something happens to check you, to make sure you're okay."

As telehealth was so new at the start of the pandemic, there was a lack of hermeneutical resources to describe something that would have been quite simple face-to-face. As with Amy, Lyla found it difficult to put into "talking words" embodied sensations. This led to her feeling like telephone appointments were not "real doctor's appointments", demonstrating how a lack of hermeneutical resources can lead to a perceived lack of credibility.

When there is little to no access to shared hermeneutical resources, as with autistic patients and non-autistic health care practitioners, autistic patients can be subjected to hermeneutical injustices. Here, I focus on three types of hermeneutical injustice:

- **Conceptual:** Conceptual hermeneutical injustices occur when there is a gap in the collective hermeneutical resources to describe or make sense of experience.
- **Contributory:** Contributory hermeneutical injustices occur when minoritized groups have a way to describe or make sense of experience, but dominant social groups – in this case, neurotypicals – either ignore or dismiss these concepts.
- **Expressive:** Expressive hermeneutical injustices occur when the *way* in which something is communicated is implicated in misunderstanding and credibility rather than the semantic content of *what* is being said.

See Catala et al.'s (2021) paper for a detailed description of these and other types of epistemic injustice and how they relate to autistic experiences.

Iestyn's account of his difficulty in using numerical pain scales provides an example of a conceptual hermeneutical injustice:

> "I didn't actually quite know how to respond. Quite often, you know, asking those kinds of questions like you know, 'How much does it hurt?' Well I don't know. I don't know, as we've discussed before, the

> one to ten pain scales are difficult for a lot of us, like, you know. Certainly difficult for me."

The assumption that numerical pain scales are helpful for all patients underpins their heavy usage within health care (Karcioglu et al., 2018). Despite autistic people – as with Iestyn – claiming that they are a barrier to them effectively accessing health care (Kalingel-Levi et al., 2022; Nicolaidis et al., 2015), they uncritically remain in use. When asked how his experiences could be improved, Iestyn elaborated on his difficulty using pain scales, first highlighting the lack of shared hermeneutical resources, which contributes to the Double Empathy Problem as health care practitioners fail to understand the difficulty their autistic patients are having. However, he concludes that he is "just not very good at interpreting what pain is," which is indicative of Iestyn internalizing the status quo that autistic people inherently struggle to do this rather than it being linked to the lack of shared hermeneutical resources:

> "[T]ime to ask what on earth is meant by moderate … you know a benchmark to put it against. It's the lack of benchmarks that do my box in with these kind of, you know, quite painful, very painful, not painful at all type of things. You know, I'm just not very good at interpreting what pain is really."

Pink Princess also provides an account of her experiencing conceptual hermeneutical injustices. She describes being unable to ask for help because, without access to collective hermeneutical resources, there is not a way for her to do it:

> "Yes, but I didn't know what I was asking for. Looking back, I wasn't asking for what I actually went there for. I said I needed confidence, I needed these things. In actual fact, that was probably me starting to come out to say that my [Life event 1], I'm not coping. I need support. But I have none of that vocabulary to be able to ask for it."

While Iestyn and Pink Princess problematized the breakdown in communication in themselves through their accounts – Iestyn believing that he was unable to describe pain, and Pink Princess saying that she lacks the required vocabulary to seek help – Sarah told a story of her experience of her health care practitioner taking no responsibility for the success or failure of their interaction. Sarah described how she needed to provide contextual information to be able to describe her pain. She explained to her health care practitioner that she needed to give this extra information but she was cut off during her account. Sarah’s health care practitioner did not allow her to respond to his question in the way she needed to make sense of, and make intelligible, her experience. Instead, he belittled Sarah as she tried to get help for her painful condition:

> “Then he said to me, ‘Would you say your pain is the same as it was?’ So it almost felt like I was in a courtroom being examined by a barrister who wouldn’t let you give the full answer and it was only what they wanted to hear. So I said, ‘Well, when I was referred by my doctor, the pain was different and it was so severe I couldn’t cope.’ So he said, ‘Well, can you cope now?’ And I said, ‘Well, yes. I’ve got used to the pain, but when you’re autistic your sensory experience is different and I have a very high pain threshold, but that doesn’t mean to say I’m not struggling with pain because I’ve noticed it. You know, the pain has affected my life considerably and that I’m not able to do some things because of what the pain’s done.’ And then it was just like he kept repeatedly asking me he wanted a yes or no answer. So eventually I just said, I agreed to stop him asking me the same question over and over again because I thought, well maybe he doesn’t understand what I’m saying.”

Sarah’s account is an example of a contributory hermeneutical injustice. While it is known that health care practitioners subject their patients to epistemic injustices and complain “that patients’ speech is full of irrelevant information” (Carel & Kidd, 2014), Sarah being openly autistic with her health care practitioner makes her account specifically an example of a contributory hermeneutical injustice. Sarah explained that autistic people are more likely to use more words when communicating due to a fear that they will be misunderstood, sometimes described as “over-explaining” (Price, 2021). Health care access literature contains several accounts of autistic people being misunderstood during health care interactions (Ali et al., 2022; McMillion et al., 2021; Strömberg et al., 2021), which might lead to an autistic patient ‘over-explaining’ to be understood. Despite this, Sarah’s health care practitioner refused to acknowledge these concepts and required that Sarah meet neuronormative communication standards that were not possible – or warranted – resulting in a failed health care interaction.

Sarah describes how the concepts that she drew on to describe her pain, including her sensory processing differences making her pain threshold higher than typical, were ignored. Instead, her health care practitioner continued to insist that she communicate the way he wanted: only to provide a ‘yes’ or ‘no’ answer, implying that the other information she provided was viewed as meaningless (Catala et al., 2021). This dismissal of Sarah’s capability as a knower of her pain experiences by her health care practitioner, while he displayed a clear lack of empathy, led to an instance of testimonial smothering. Sarah just “agreed” with what the health care practitioner was saying to “stop him asking [her] the same question over and over again”. This was also experienced by Iestyn, who wondered if it was “worth bothering at all” seeking health care.

Running through most of the participants’ accounts were instances of being subjected to expressive hermeneutical injustice. This issue has been researched previously, though not labelled as such, particularly as a non-standard performance of pain meant that it was assumed that autistic people did not feel pain (e.g. Goldschmidt, 2017). This assumption was bolstered by health care practitioners and parent/carer reports of their autistic patients/children, which is suggestive of the link between testimonial injustice – particularly preemptive testimonial injustice – and hermeneutical injustices. Furthermore, I believe that expressive hermeneutical injustice is most likely to be linked to the Double Empathy Problem, as those subjected to it are most likely to be perceived as in a ‘breach’ of social norms.

Daisy provided an account of her performance of pain leading to her being worried that her health care practitioners are less likely to believe her:

> “I think written appointments would be way more helpful on this because then they’d have to just go on my words. On the phone I sound competent and articulate when I’m on my game, and so if I said I was in pain they might not believe me because I know that I can give birth to children without making a sound or looking distressed, but they don’t know that.”

Daisy is describing her fear that the way she ‘performs’ illness would be seen as illegitimate (Hillman, 2014). As the expected presentation of pain is based on neuronormativity and implied communicative normalcy, Daisy's fear is quite rational, particularly as she is also a health care practitioner and is more aware of these concepts and the idea of legitimised performances. Indeed, there is evidence to suggest that the different presentation of pain and illness from many autistic people is misinterpreted by health care practitioners, leading to poor health care outcomes (e.g. Ali et al., 2022; Knight & Steward, 2021).

Scragger told a story regarding how the way they express their anxiety – and the resulting expressive hermeneutical injustice they faced – led to testimonial smothering:

> "[W]hen I'm anxious and confused and scared they seem to interpret my tone as anger and confrontational very quickly over the phone when, I guess, when they can see me you know they can tell I'm anxious. I mean I still scare some people. I've been kicked out of one clinic because you know they couldn't cope with my stimming but over the phone it's amplified. So I've had situations where I've been told to calm down where I've been told that if I don't control my tone and speak appropriately the call will be ended. I mean, what do you do with that? What do you do when you're just terrified and you're trying to convey? Yeah, I find it hard to explain what's going on in my body anyway. So I always sound anxious when I'm trying to describe something that I find really difficult to describe. So the result is, I do not call the doctors for myself very often at all."

Scragger provides an account of how conceptual hermeneutical injustice – being confused and struggling to make themself understood during health care appointments – leads to anxiety. The stimming and change in vocal tone that accompanies Scragger's anxiety leads to expressive hermeneutical injustice whereby Scragger's health care practitioner does not correctly interpret their anxiety but instead interprets Scragger's vocal tone as aggressive and threatens to terminate their telephone appointment. This threat and accompanying increase in anxiety, for Scragger, has led to another instance of testimonial smothering; Scragger "[does] not call the doctors for [themself] very often at all," an outcome that could be considered an "epistemically justified mistrust of health care providers" (Annesley, 2020).

However, Scragger’s account is not only an example of epistemic injustices. It is also a clear instance of a health care practitioner demonstrating a lack of empathy for their autistic patient due to a lack of mutual understanding and reciprocity. I believe this indicates the link between epistemic injustice – particularly hermeneutical injustice – and the Double Empathy Problem. Scragger’s tone being interpreted as aggressive – a ‘breach’ of appropriate patient communication – likely stems from the dominant social group (neurotypicals) being sole contributors to the hermeneutical resources determining ‘correct’ communication and is potentially exacerbated by (un)conscious bias against autistic communication styles. This bias leading to incorrect health care practitioner interpretation is suggested later in Scragger’s interview when they tell me that they and their husband “were suddenly being accused with all of these things, and the only thing that had changed was that [they] were now diagnosed autistic.”

Despite the overwhelmingly negative accounts from my participants, there were some descriptions of good practices which improved their access to shared hermeneutical resources and, therefore, their access to health care. Pink Princess’s account of her experiences provides an example of how difficulties in communication between health care practitioners and autistic patients are not due to inherent deficits within the autistic patient. Rather, they are due to a lack of access to shared hermeneutical resources. When this lack is addressed, and there is a shared language and understanding, communication breakdowns are mitigated:

> “If you don’t have that vocabulary, you can’t ask for the help that you need. So in the EPA one, because it was all around how the [Life event 2] was happening – again, not pleasant – but I knew the vocabulary to use. Whereas before, I didn’t, and if you are accessing telecare for the first time without 18 plus months of knowledge and knowing that you need to, you’re not going to say the right thing, and the person is not going t– unless they can crack you, and most people would not open up to you, you’re not going to get the right answer.”

Pink Princess talks about her journey of understanding and gaining access to the required hermeneutical resources over the course of 18 months while being supported to access specialist health care services. Through this time, and a willingness from the health care practitioner to accept her testimony and enable Pink Princess to contribute to collective hermeneutical resources, Pink Princess's access to health care was improved. Pink Princess went on to explain that the support she received enabled her to explain that she *does* have emotion, but that it looks different from non-autistic emotion. Before this support, Pink Princess thought she "[didn't] do emotion" and, therefore, her need for emotional support was invalid:

> "But there's a lot of um, for anyone and especially for me who was autistic, who went, 'I don't do emotion.' Er … I do do emotion, but my emotional bar is a lot higher than other people. So it was like, 'You don't do emotion, you shouldn't be feeling like this, you should just be getting on with life, it doesn't matter, etc..'"

Pink Princess's health care practitioner's empathetic support to enable her to access the concepts and vocabulary needed to seek support for her emotional wellbeing is an example of an "epistemically just practice" (Carel & Kidd, 2014). Their good practice avoids the potential for testimonial smothering, as Pink Princess felt supported rather than rejected, and mitigates the potential effect of the Double Empathy Problem through the health care practitioner engaging in "true reciprocity" (Gernsbacher, 2006).

Conclusions and suggestions for improvements and future research

The Double Empathy Problem, the societal pathologization of autistic communication, and societal structures built around neuronormativity cause autistic people to be excluded from collective meaning-making processes through testimonial injustices. This creates hermeneutical injustices that can lead to both autistic patients and their health care practitioners lacking the hermeneutical resources to fully understand their health care needs, resulting in disparate access to health care and poor health outcomes.

The link between testimonial injustices and hermeneutical injustices are discussed in the health care literature (e.g. Annesley, 2020). In the case of autistic patients, I believe that the issue is twofold: autistic patients lack the terms necessary to describe their experiences, such as Iestyn finding it difficult to use pain scales, and health care practitioners lack the hermeneutical resources to understand autistic experiences as described (conceptual hermeneutical injustice). Health care practitioners then dismiss or disbelieve their autistic patients (testimonial injustice); for instance, ACP16’s health care practitioner requiring proof of ACP16’s autism diagnosis, perpetuated by the assumption that there is a ‘correct’ way to perform illness and pain to be deemed legitimately in need of health care (Hillman, 2014), a performance standard autistic patients often fail to meet (expressive hermeneutical injustice). Being dismissed or frequently misunderstood by health care practitioners can lead to autistic people choosing not to seek health care or to ‘go along’ with what their health care practitioner says, resulting in unmet health care needs (testimonial smothering), as seen in the examples from Sarah and Scragger. Furthermore, the lack of empathetic reciprocity seen from health care practitioners towards their autistic patients is also indicative of the link between epistemic injustice and the Double Empathy Problem.

Carel & Kidd (2014) talk about how “ill people are more vulnerable to hermeneutical injustice” as it can be difficult to communicate the complexities of illness experiences to those who have no embodied experience of it themselves. This can transfer to autistic people trying to communicate the complexities of autistic experiences. As with the triple empathy problem Field (Shaw et al., 2023), this will have a compounding effect, arguably placing autistic patients at even greater risk of being subjected to hermeneutical injustices. To mitigate this, health care practitioners should follow the example of Pink Princess’s health care practitioner and aim to become “testimonially just clinicians” (Carel & Kidd, 2014), whereby they are sensitive to the possibility of a lack of hermeneutical resources being the cause of communication breakdowns between them and their autistic patients and do not dismiss their autistic patients’ credibility as knowers. They should not assume that their autistic patients are communicatively incompetent but should also provide reasonable adjustments – such as Daisy’s suggestion of written communication – to facilitate reciprocal communication. By supporting patients to understand and talk about their experiences, for example, using tools such as the phenomenological toolkit designed by Carel and Kidd (see Carel & Kidd, 2014), autistic adults’ access to health care will likely be improved. Furthermore, health care practitioners need to believe the testimony of their autistic patients; in other words, they need to give them the benefit of the doubt. If autistic patients are not believed, they will not be enabled to contribute to collective hermeneutical resources, meaning that they will continue to be misunderstood, perpetuating the disbelief.

That said, there must be care to ensure that these issues are not solely individualised within health care practitioners, just as communication breakdowns should not be situated in individual autistic patients. Rather, it should be acknowledged that current health care structures uphold and reproduce epistemic injustices (Carel & Kidd, 2014) due to being designed around neuronormativity and communicative normalcy. For autistic people to be understood, neuronormative assumptions need to be made visible and questioned. To do this, future empirical research into the Double Empathy Problem could be conducted using a lens of epistemic injustice, particularly within health care settings. Ideally, this research should be observational to capture the interpersonal nature of communication. To avoid perpetuating hermeneutical injustices, research teams should include autistic members, and all projects should be coproduced with lay members of the autistic community to ensure an emancipatory approach and to redress epistemic injustices within autism research.

Autistic people need to be seen as credible and reliable testimonial agents. They must be enabled to contribute to collective understandings, that is, the hermeneutical resources that both speakers and listeners draw on to ensure mutual understanding. A greater contribution to collective understanding from autistic people will likely result in improved reciprocity, a reduction in testimonial injustices, and fewer instances of the Double Empathy Problem.

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