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Research Article

THE HUMAN SPECTRUM

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ABSTRACT

Introduction

Autism has typically been characterised by its external manifestations rather than experienced phenomenology, with consequent impacts on both research and practice. There have recently been increasing calls for more phenomenological enquiry in autism, but little actual work reported.

Method

A shared participatory phenomenological self-investigation, by the four authors, of lived experience across the autistic/non-autistic divide. The sample size was chosen as necessary for the feasibility and acceptability to participants of such work in this context. Roles of ‘researcher’ and ‘interviewee’ were purposefully alternated between participants to establish trust and reciprocity. Initial phenomenological reduction or bracketing was applied to the description and recording of each participant’s intimate lived experience in a number of key domains across social relationships, the physical environment, development, and in adult life. These experiences were shared within dialogue to open them to investigation and questioning from the others, with alternating interviewer and respondent roles. A third step synthesised these shared observations across individuals into themes of continuity and difference.

Results

A number of emergent themes, such as the need for trust and reliability, and the impact of context on regulation of emotion, sociability and empathy, showed striking commonalities between all participants. Other themes, such as primary sensory experience and social joining, pointed up more clear differences between autism and non-autism in development and the adult world. Themes of interest-focus and attention were marked by both commonalities and difference.

Conclusions

This shared phenomenological method was taken as a first step within a new area of active investigation in autistic phenomenology. It proved successful in eliciting detailed information on self-experience. The results suggested hypotheses for a new understanding of autism within the wider “human” spectrum of experience; for instance, the common basic need for trust and social connection, but striking differences in sensory experience. It suggested that

some characteristics long thought intrinsic to autism, such as social mis-perception and reduced empathy, may be alternatively understood as state-dependent outcomes contingent on specific contexts and interactions. Implications are suggested for testing in further research, developmental theory and intervention practice.

INTRODUCTION

From its earliest descriptions in young children, autism has been characterised in the medical and scientific literature, for instance in the nosology of International Classification of Diseases [1] and Diagnostic Statistical Manual[2], by its externally-observed manifestations rather than its experienced phenomenology. In recent years, a counterbalancing towards the importance of lived experience has begun in the form of an increasing prominence of autistic self-advocacy and the broader neurodiversity movement,[3] but also from clinicians and researchers, advocating more work in this area.[4,5,6,7] This serves to point up the striking lack in the literature of a formal phenomenology of autism or systematic enquiry into its lived experience, which has undoubtedly led at times to a “mindless”[5,8] theorising in autism research and practice, and not just with young children. A term like ‘neurodiversity’¹ contains the paradox of appealing simultaneously to a neurological difference whilst seeing that difference as an aspect of diversity to be included within, as we call it here, the “Human Spectrum.”[9] Nor, when we consider the complex processes of development, can it be sufficient to define human

¹ A note on terminology: in this paper we use neurodiversity in the specific context of autism. This means that when we refer to the spectrum of neurodiversity, we refer to the spectrum going from neurotypicality to neurodivergence in a specifically autistic sense. Our specific use of these terms fits the scope of the present paper focusing on differences across the autistic/non-autistic 'divide'. We acknowledge that the terms neurodiversity and neurodivergence should not in general be used only in a context of autism and that many other neurodivergent people - whether autistic, Tourettic, dyslexic, ... - are part of the overall human spectrum of neurodiversity. That said, as in this paper we have only investigated the autistic element of neurodivergence, our terminology needs to be interpreted in this restrictive sense. We believe that the points made here may extend to many - if not all - other neurodivergent people (thus making up for the intuitive appeal of a term like 'spectrum of neurodiversity' - but doing so will require separate analyses. Meanwhile we believe it is justified to use the terms in their restricted sense given the fact autism historically was the area of first analysis in this domain. We are grateful to an anonymous reviewer for pressing us on this point.

diversity just by individual differences between brains.[10] Milton et al, 2012[11] noted a ‘double empathy problem’ in the way that disorder-defining concepts such as a ‘lack of social understanding’ need to be understood in the context of a common lack of a reciprocal empathy from the wider community to autistic lived experience.

Our paper aims to address these issues with an innovative phenomenological enquiry to uncover divergences *and* continuities across the autistic/non-autistic ‘divide’ (that also runs across the authors). It represents an exercise in exploratory phenomenology and participatory sense-making[12,13] where we ‘let each other be’ across our respective differences[14] and work together to explore our own and each other’s experience.[15] In doing this we also undertake the practical first steps in a quite radical form of the collaborative and co-constructed enquiry often now advocated for the field.[16,17] The implied provocation within our title reflects a central question that arose early in our inquiry: “How to characterize a difference like autism without constraining the freedom of identity or action of those falling on either side of its definition?” Our conclusions suggest how tackling developmental issues with a shared phenomenological approach in a context of mutual trust can inspire theoretical, empirical and therapeutic ideas. We specifically propose a notion of ‘intervention’ that focuses on restoring the necessary conditions for such mutual understanding and development.

METHODS

Our method in this initial study was to set up an open, shared phenomenological exploration across the range of neurodiversity/neurotypicality; an enquiry following van Manen[18] in being active, engaged and formative. The participant-authors gathered together purposefully as four individuals with lived experiences across the spectrum of neurodiversity (three identifying as autistic, one not). We aimed to explore our mutual lived experience, and also the experience between us in the group, in as much depth and detail as was possible. The sample size of our group was selected according to what the participants felt would be feasible and comfortable to manage the method, and the depth and complexity of interaction and level of experience that we planned to share. In this we followed the view that ‘less can be more’ in phenomenological research[19] and that sample size should be contextually appropriate.[20] Extending other methods, we undertook the enquiry reciprocally as a group of peers, dispensing with fixed roles of ‘researcher’ and ‘interviewee’;[7,21] rather alternating these roles between us as we proceeded in a process akin to what has been termed

a ‘dialogical’ method.[13,15] This method generated an intersection of viewpoints in depth from four people with diverse experiences: from personal to clinical, from being and feeling to researching and teaching; and diverse intellectual backgrounds, including: medicine, psychiatry, philosophy, linguistics, education, neuroscience, anthropology, sociology, education and autism studies; constituting what Halling^[15] calls an ‘empirical variation’. Rather than aiming for a simple comparison between autistic and non-autistic experience, we aimed to explore and clarify our experiences through dialogue, learning about similarities or differences and adapting our narrative as we proceeded. For this reason too we decided not to identify the particular source for the excerpt quotes in our results section.

As in any phenomenological enquiry our first step was to, as far as possible, apply the phenomenological reduction or bracketing, to “suspend beliefs or theories about experience” [17,21,22,] in recording and each describing our lived experiences in a number of key domains. The second step was to share these experiences between us, and to open them to clarification and questioning from each other, alternating interviewer and respondent roles as we went, and making a written record of each step. The third step was to synthesise these shared observations across individuals into themes of continuity and difference. Because of the COVID-crisis, the investigation itself was primarily done during monthly 1.5 hour video conferences between March and November 2020. Prior to these online meetings, the work had begun by exploring through in-person dialogue what it was like to be in a particular room or environment and in the presence of another, focusing on the quality of experience of the physical world, our attentional focus, and how we managed the presence of other human beings from moment to moment. Analysis of the dialogue record and thematic elaboration was undertaken through video conferencing between November 2020 and May 2021. This work has therefore been integrally co-produced, with three out of the four participant authors autistic adults and members of the autistic community.

RESULTS

Our dialogue covered experiences of relating to other humans, groups and crowds, the physical world, and the influence of perceptual experience on reactions and expression. We touched on diverse areas of social belonging, interests, autism-specific environments, preoccupations, empathy and extreme states of mind. Six key emergent themes were identified: “Trust”, “Sensorium”, “Interests and Attention”, “States of Mind”, “Social

Joining” and “Emotionality” (shown in Figure 1). Themes of Trust, Emotionality, and States of Mind emerged as broadly shared across our human spectrum; themes of Sensorium, and Social Joining proved to be relatively distinct between autistic and non-autistic experience. The theme of ‘Interests and Attention’ in particular combined overlaps and differences; but these were also present in the other themes and the division just highlights how gradual differences tend to give rise to the different qualities of experience on different ‘sides’ of the autistic/non-autistic ‘divide’. We document the themes below with attention to the overlaps and differences that marked the quality (in all senses of the word) of the exercise.

Figure 1 about here

Trust

A first-emerging theme from our investigation was a realisation of an equally shared need for *Trust and Reliability* across our human spectrum. This applied to both interpersonal social and physical environments.

“For me the strongest feelings of connection that I have had is with family members, particularly my own children – in terms of emotional bonds but also a sense of similarity (being more like me than anyone else I have met). My son being autistic with severe learning disabilities probably being the strongest of all connections – and yes I would say this is reciprocated (if not symmetrically).”

“A powerful way of connecting with others is through my interests in life, whether that be table tennis, music collecting/appreciation and so on. Indeed, another bond I have with my son is our love of music and rhythm – from taste in music to singing together (where he is more verbal than with usual speech). We are both highly sensitive to sound and that brings similarities in what we struggle with but also what we appreciate. My son and I are obviously different from one another in important respects too, but this does not detract at all from that feeling of connection and the strength of similarities in other ways.”

The feeling of trust extended to inanimate objects.

“I also feel deep connections to inanimate objects, – so for example my table tennis bat collection is something external to me but also an extension of me adding to affordances

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and capabilities – and yes I am deeply connected to my favourite bats! The blade (wooden base and handle), the rubbers and their properties and so on.”

Experiencing non-typical attributes could be a challenge for Trust.

“I’m left-handed and grew up early in a world where to some extent right-handedness was imposed at primary school. I remember this as a definite, somewhat difficult challenge, how to adapt my left-handedness to a right-handed world; to graft my internal organisation onto an external requirement and ‘fit in’. I remember the psychological effort this required.”

There was striking commonality between us as to the experience in our lives of what promotes trust. We needed also to establish this practically between ourselves at the outset, as a high level of mutual trust was essential for the project to work. We felt that an interpersonal environment for trust needed above all to be alive, attentive, accepting; we all depended on feelings of predictability, reliability and care. When these were hard to come by, we could all describe the sudden feeling of a lack of trust, which might lead to reliance on self-management and certain routines or rigidities; but we all had different thresholds for this. We could all tolerate environmental change, but it needed to be relatively fluid and predictable. No environment, human or physical, could be ‘perfect’, but it needed to be sufficient for us to feel ‘anchored’ in it. We were all sensitive to very much the same kinds of environment determinants, such as familiarity of routines and safe kinship - but to different degrees:

“The barrier to resync then, I feel, is a lack of trust in the sense of a lack of being able to return to reliability. Things or movements may play a role here but it’s persons that make all the difference. If you can ‘count on’ people to cut you some slack (and vice versa) you can explore or venture out knowing they are a pivot towards reliability (i.e. they can be ‘trusted’). I believe this has to do with being open (on both sides) such that your boundaries can be malleable, knowing you can get back to ‘safety’.”

We found that a state of trust therefore resulted from a combination of self and environmental characteristics or ‘setting conditions’; that the same environment could be experienced as trustworthy or untrustworthy for each of us differently, depending on how we imagined it to be. Failing that, the environment could be experienced as a threat; unpredictable enough to need vigilance, intense enough to need self-protection. If such a feeling persisted, we were all, autistic and non-autistic, prone to the deleterious effects of an ensuing chronic stress.

Sensorium

We developed the use of the term ‘sensorium’ as a mutually agreed way to cover the totality of our subjective sensory experience and processing of the world, both interpersonal and physical. We found that this was a domain in which the differences across our ‘spectrum’ were amongst the most defined and early emerging. They have much to do with one’s sense of developing an implicit awareness of one’s own being-in-the-world:

*“I *hated* wearing shoes for the first 5 years or so of my life and always took them off when possible and continued a barefoot preference throughout my teens. I have always cut labels from all clothes, nothing even slightly scratchy - my mother also accommodated this as a real need. (..) Fake flowery smells - I have often entered a shop and immediately left it because some ghastly perfume is being pumped out and it makes me feel sick; petrol smell does too; laurels in bloom, ditto. The seeds in figs, the fuzz on peaches, the slime of avocados and the different slime of okra, cannot be ignored! The very thought of them can make my gorge rise... “*

We talked about how these acute sensory feelings² are directly pertinent to what we termed above the ‘setting conditions’ for trust. The autistic experience was rife with abrupt discontinuities that often feel incompatible with a sense of trust and which are experienced as direct threats to a sense of self in the world. Yet, even in this domain, where there were substantial differences in the quality of perceptual experience, we also found a common ground of experience across our human spectrum. For instance, we all experienced ‘flow states’, that sense of immersion when integration of the sensory world falls deeply into line with one’s flow of attention (Csikszentmihalyi 1990); what differed was the frequency of those states and what it took to enter them. We also shared experiences of self-in-space; the point where one feels precisely “right”, comfortable and most “real”. We all additionally had experiences of self-environment alignment, where exteroception links to an internal sense of self:

“What I noticed walking at night is that I move forward in a succession of ‘meaning frames’. That is, as each moment of external sensory experience ‘clicks into place’ (becomes recognised or makes sense, as say a lamppost, as leaves moving in the wind

² Our investigation confirmed the centrality of autistic sensory experience which, although now subject to much greater attention, we note was only added in the Fifth edition of the DSM-5^[2] and may reflect how autistic lived experience has been relatively ignored or downplayed historically compared to observed social-communicative and behavioral rigidity.

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and light, or as wet light on tarmac), I simultaneously then have a sense of myself actually existing in that space and in that time. The very experience of it 'making sense' is simultaneous with me feeling located as a self." (emphasis as original)

The sensory experience for those of us autistic was much more acute, difficult to integrate, and often associated with abrupt loss of trust in the self-environment flow. That said, this 'acuteness' was not experienced in and of itself as always negative; it could also lead to a blissful sense of flow with the sensorium, and via the sensorium, with others:

"I have hyperacusis/hypersensitive to certain sounds – my son even more so. But also a major source of joy – e.g. picking out what a particular instrument is doing in a favourite piece of music."

We all shared how habitual, repetitive, and even obsessive preoccupations or behaviours can be stress relieving, and how we can all use them for this purpose. But the frequency and idiosyncrasy of this differed greatly, and we noted how often they can, at the extreme, find themselves at odds with social conventions or rules.³ We felt that intense interests can be understood as an extreme way of locating oneself in space/time and organising one's experience into something more coherent:

"Cushions, towels have to be ordered in alternating colour patterns. Lights have to be switched off & on in specific orders. Volumes need to be controlled in even numbers (or multiples of 5 - but only if also a multiple of 3 or even). (..) I'm chaotic & messy but if something is out of place, I notice it immediately. It bothers me. It shouts at me. "

We found that this markedly different sensorium experience between us was intimately linked to how easily we could imagine a trustworthy environment and that it also influenced the nature of our attention and interest.

Interest and Attention

The dynamic between the divergence in sensorium experience and the commonality of looking for trust linked to a theme around patterns of attention, absorption and intense interests. Autistic experience in this regard seemed to be related to intense attentional peaks and interest

³ When we use the term social conventions we specifically refer to the neuroconventions of sociality which are implicitly presupposed by the dominant majority of neurotypical individuals with respect to normative standards of relationality, see McDermott (2022).

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absorption.[23,24] Non-autistic experience appears to make easier shifts of attentional focus according to environmental, including social, demands and contexts, but can also have times when attention can become overly fixated:

“You talked about how the attentional focus can be so strong as to completely blot out the social environment - making the autistic person seem 'non-social' - I also talked about how I've learned that my attention if over-fixed or absorbed can be felt by others as socially dismissive too - so I have to be aware of how and when to disengage and pull back to the interpersonal focus....We agreed that the inter-personal can be extremely interesting for the autistic too; and the attentional focus on this then can produce insights and a quite rigid starey attention - eg 'fixed' gaze.”

We learned that a difference here then was not so much in the process of attentional focus, but rather in the way it evolved dynamically to be attracted more strongly to specific interests. When we as autistic felt driven out to sea without these anchors, a profound anxiety-provoking disorientation ensued.

“Both sensory and quasi sensory channels (think singing a song in your head for a super obvious case) can attract one's attention at any given moment and so can emotions and so can cognitive/communicable content and so can body system messages like pain or hunger.”

Attentional feedback loops in those of us autistic seemed to lead to more pronounced interests, which could be mistaken for a lack of social interest by misattributing the frequency of states of mind, at odds with a typical interest profile, to a stable trait. We turn to these states of mind next showing that they actually showed, like trust, commonalities throughout the human spectrum.

States of mind in context

Our shared phenomenology led us to an understanding that experiences of empathy and other-directedness (and disruptions to both) were common for all of us. We had all experienced subjectively how cognitive or sensory overload can temporarily reduce other-directedness, making us seem self-absorbed and unaware. It became clear to us that, in some situations, an apparent ‘empathy deficit’ was really more a ‘preoccupation surfeit’, and that the dynamics of this were recognisably common between us:

“I was trying to come back from a burn-out. Part of my routine was going to the fitness, headphones blasting music-of-the-moment. This anchored me. One time all was peaceful at home when I left less than peaceful in my mind. I was happy that - by the time I came back - I was focused, bursting with ideas to share with my family. When I took off my headphones I got right to it, my wife and daughter sitting in the kitchen. They didn’t quite respond but I thought this must be because I didn’t explain myself clearly. So I powered on trying to improve the way I phrased my ideas, only to feel something was off. My daughter left the kitchen. My wife stared at the floor. I got mad. Why not cut me a little slack? My wife cried a little. That stopped me dead in my tracks. A blooming, buzzing confusion ensued; a pile-up of reasons which I thought could explain why slack was not being cut this time, stacked together with a great many things which were as usual physically out of place (& for which I did cut them slack). I started frantically pacing up & down the room whilst, as frantically, scratching my head; & I felt my voice had dropped an octave or 2 when I mustered asking ‘What have I done this time?’, ready to give up on it all. Then my wife: ‘If you had given us a second we would’ve been able to say our daughter thinks she doesn’t have enough time to prepare her exam. Now she is even more distressed because she thinks she has wronged you.’”
(emphasis in original)

We came to feel that confusing such contingent states of mind for fixed traits or personality characteristics explained much misunderstanding; for instance, that the differences in social behaviour between neurotypical and autistics were essentially due to intrinsic or innate social deficits or preferences.

Social Joining

Our investigation explored experiences as regards the phenomenon of ‘social flocking’^[25] everyday social alignment and group flow, including how to approach, join, take turns, repair, break off and leave (an everyday capacity to get by in a social world). While this was recognizably not a given for any of us, the experience of early joining and social motivation, an ease of basic ‘flocking’, say in the pre-school years, felt like a point at which our autistic and non-autistic experience and trajectories began to diverge in important ways. The complexities of joining also revealed a fine line between reaching out authentically and creating what can rapidly become felt as a socially awkward situation.

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“Weird examples from my childhood, wanting to help. At 6 or 7, giving away my shoes to a weeping girl [a complete stranger] because hers had been thrown in the canal and she was frightened of going home without them. I wasn’t frightened for myself in the least. We were not in the precariat, and also my mum typically accepted my choices.”

Loss of joining can lead remarkably rapidly to acute feelings of social isolation across our spectrum including non-autistic:

“.....spending one New Year’s Eve alone in a seaside town thinking I would meditate on the turn of the year. But then hearing the sounds of groups of social celebration, of laughter around in the street - and suddenly, just like that, falling into an intense sense of loneliness and isolation from the rest of the crowd (and ‘society’) and a sense of personal failure (although irrational) for not being in the social swarm at a point where everyone is doing the same thing in a ritualised way.”

Where for the participant at the neurotypical end of the spectrum, there is often a sense of converging intuitively and effortlessly with social norms and conventions, for autistic participants this was associated with something requiring expenditure of intentional energy to create occasions of ‘togetherness’.

“An adolescent memory: I could never quite figure out why other students walked one way or the other so I was mostly left behind feeling awkward & alone. At some point I was fed up of being alone (I didn’t want to be alone, I wanted to be in on it). I pre-empted all of the scuttling out of the classroom to wherever they went. I just up & left. To my surprise, quite a few classmates followed me & I suddenly was the centre point of a group! That made a big difference.”

The vagaries of social conventions themselves could become an acute interest, for instance related to gender stereotypes:

“... in primary school with the games the others played, I was not getting what other girls were on about nor getting what the many guys around who fancied me were feeling. But I did try to find out in a number of ways from my late teens for a few years. These were areas in which only obeying rules which made sense to me became interestingly irresponsible. I didn’t get that there should be any fuss about which types of gender connection were going on sexually. I felt fortunate to be able to wear male

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clothes at will after getting over the early teen surprise of realising I was going to have to turn into a woman.”

All participants shared experiences of autistic-adapted spaces, like Autscope (<http://www.autscope.org/>), and this led to emergent themes on the importance of the nature of accessibility in social spaces; such as clear signalling and adaptations to reduce sensory overload.

“One thing is the labelling – being able to carry on one’s body a written signal communication that ‘I want to talk’, ‘I don’t want to talk’, ‘I don’t want to be disturbed’, ‘please start a conversation’, ‘please wait for me to start’. Social signalling more than anything else in concrete visual rather than inferential prompts. These communication prompts clarify a lot of the uncertainty in the ‘cocktail party’ space? Then the efforts to adapt the social environment to be less stressful at a sensory level – with time out, and regulated lighting and spaces.”

So, the phenomenon of social joining seemed often to be experienced differently, but this did not seem to be a distinction reflecting intrinsic motivation, but rather that of developmental trajectories shaped by repeated mutual misunderstandings. As one of us put it, we should not forget the commonality throughout the human spectrum that *“Not being able to bring one’s gift to others does deep harm to people’s lives.”*: a deep feeling of rejection and loss of trust.

Emotionality

The theme of social joining and its disruption highlighted a crucial capacity in all our emotional lives of being able to channel internal states into a socially meaningful and socially accepted communication. Any block to this channelling led rapidly in all of us to a sense of building internal pressure:

“Tension, release and channelling – The experience of internal pressure, and this internal tension leading then to abrupt or awkward reaction; how disruptive this can feel in the social space and how easily leading to my personal sense of being a ‘social disruptor’ (and how other people see me).”

We considered the importance of having a social niche or context in which it feels comfortable to be able to channel such internal frustration into social communication or action; a context that allows the internal to be made external in socially accepted and meaningful ways. Also

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how the lack of this can easily progress to a catastrophic decompensation that can be described as ‘meltdown’.

“...imagine walking happily through a favourite place, birds singing, tra-la-la – and your next step, without warning, sends you tumbling into a deep psychological hole which other people cannot see at all. You have absolutely no idea what just happened or how to get out. Everything is lost and there is no trace of a way back. Some recovery time will be vital.”

We experienced similar episodes of overwhelming disorientation across our spectrum, including in non-autistic life when the conditions are sufficient:

“Falling off my bike for instance a few months ago....at one moment my experience is of me on the bike, the movement, space around, the road, time, wind, an overall gestalt of ‘me being on the bike’Then suddenly ‘the next thing I know’ I’m on the ground, upended, completely confused. I ‘come to’ consciously simultaneously with realising in a split-second ‘where I am’; on the ground looking up at the bike, vaguely realising that the front wheel is bent at a crazy angle, feeling the road and after a time the pain. A narrative clicks into place in my mind; ‘I’ve fallen off’ and the disorientation begins to clear. But the couple of seconds between hitting the road bump and hitting the road has completely disappeared; not experienced because not processed, during this time I literally didn’t exist.“ (emphasis in original)

Such sensory and bodily discontinuities, singularities, are shared across the human spectrum, but for autistic people, being overwhelmed is likely to be more frequent, or prompted by social interaction, and of greater intensity and duration. Trying to manage or avoid them becomes part of our everyday experience:

“The commonality I think is that of avoiding to be in a position that was unknown or overwhelming; avoiding to be in such positions is something that costs me a lot of ongoing energy as it requires me to try to be ‘ahead’ of things and make them controllable (figuratively, but also literally, going to places before I need to be in the place on a scouting mission; then making sure in actually going to the place for real that I can go there in exactly the same way).”

We all shared the further experience of burnout - but those of us autistic find it much more likely to be chronic and exhausting - finding a route to recovery in restoring a shared environment of trust.

“If autistic burnout is related to spending more resources coping than you have, avoiding burnout can’t be done alone. Mostly because many strategies people have to avoid or recover from burnout involve being able to behave like an ACTUAL autistic person, being accepted as autistic, and getting support and accommodation, all things that require the cooperation of others.”

DISCUSSION

There have been recent persuasive calls[4,5] for a more phenomenological approach to autism science, but little actual work on this to date. This shared phenomenological enquiry is we believe novel in working across the autistic/non-autistic ‘divide’, alternating roles between interviewer and interviewee, and incorporating the positionality of the participants into interpretations made. This follows a participatory ethos and reduces the impact of power dynamics.^[16,26] Our diverse experience and expertise helped to overcome misfires in communication and reduced unintentional ‘fishbowling’ of autistic experience.^[27] Reciprocally, it was important that the neurotypical participant felt that his experience was welcomed by the autistic participants, something that allowed the building of trust in the work. In clinical descriptions of autism, it is often the differences from non-autistic people that are emphasised rather than the points of connection. From this enquiry, it is striking that the quality and importance of social connection with others as preconditions for trust showed no significant difference across our spectrum: all participants described this as having a similar nature and level of importance for them. This may be counterintuitive to some readers from the medical clinical and research community, since a common feature in clinical description and nosology is still a core lack of social reciprocity or interest in social relationships. But our enquiry suggested to us on the contrary the preliminary view that trust is equally important to autistic people, but that the ‘setting conditions’ to enable trust and reciprocity may generally be more demanding; the necessity and facilitators of trust are shared, but the barriers or disruptors of trust formation, and the outcomes from its lack, differ. This is likely to be particularly the case for autistic people who, as a minority, have to grapple with ‘setting

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conditions' that are shaped in line with preference of the majority of neurotypical people. It emphasises too the sensitivity needed in navigating differences in position, power and experience between people in a 'neuromixed' environment. We identified clear differences in the social opportunities to develop such resonant and connected experiences in everyday life, with perhaps an exception in familial and intimate relationships.

The clearest distinction we found between autistic and non-autistic experience was in the quality of the experienced sensorium. Difficulties in navigating the sensory bombardment of environments not designed for autistic sensibilities were balanced by some of the joy found in autistic sensory experience and in autistic ways of approaching activities involving appreciable external sensory input (e.g. quietly reading a book in a quiet room). While this core phenomenological perspective for autistic people has been the subject of previous report and description in the medical anthropology^[28] and neurodiversity literature,^[29] it is something almost completely lacking in the current clinical and research literature. This is an area requiring urgent further elaboration as a key to understanding autistic development.

A notable difference between accounts shared in this enquiry related to the use of interest and attention, and the extreme nature of the dynamic states experienced and expressed by autistic people. These gave insight into differences in canalisation^[30,31] in developmental trajectory, with often the points of disruption and difficulty being most salient.^[31] This is consistent with the 'monotropism' account of Murray et al, 2005^[24] in which autistic attention peaks are held to be highly maintained and stable, leading to an intense absorption in specific 'interests'. While 'preoccupying interests' have been associated with a diagnosis of autism for decades^[1,2] they have had little attention as dynamic processes, except to characterise repetitive behaviours as areas of concern. Yet the experiences in this enquiry are consistent with how an intense interest can be a 'stable attractor' in dynamic system terms;^[28] a central source of joy and learning in a highly focused way, but also a potential source of related inattention and lack of transaction with others. This links to both predictive and enactive accounts of mind,^[32,33] and opens out a more developmental and intersubjective perspective on autism.^[34,35]

We found that autistic experience frequently contains times of internal preoccupation and sensory overload, preoccupations that can commonly lead (and across the human spectrum too) to relatively unempathic states of mind and reduced interpersonal sensitivity. It also seemed

likely from our accounts that, because of this frequency, others may be more likely to attribute the cause to intrinsic empathy-impairment traits rather than to states of mind contingent on context. As we shared our childhood experiences in development, the impact of receiving such repeated social attributions over time came forth clearly; in increased social anxiety, internal preoccupation, social avoidance and the internalised identification of being apart and different. As we reflected on our respective developmental trajectories, we could share the branch points and cumulative impact of such experiences, illustrations of the ‘double empathy problem’.[27, 36]

The autistic experience was characterised by a more profound subjective contrast between things going well and things going wrong. Our non-autistic member had to search his memory for incidents in which he experienced a loss of sense-making capacity, dislocation, and need for recovery time comparable to autistic members’ frequent accounts of such experiences (as in ‘meltdowns’), when experienced abrupt change means order and connection are lost and need to be found again. This has been described as being ‘ambushed’ by events and people, suddenly losing flow and continuity.[10,37,38] In response, going with natural flows and building on personal inclinations or dispositions is much more likely to create attitudes of confidence and openness that will be enabling. That is true for all humans, but we suggest that in autistic people the inclinations are steeper, attraction and repulsion are more polarised, the contrast between attention tunnels and the unattended world is likely to be more abrupt and this affects directly and via feedback loops into how attention is spread.^[24] Experiencing perceptual chaos one will seek out patterns and reliability, when under stress potentially impose them on the immediate environment in ways perceived as autistic ‘rigidity’; without anchors of perceptual consistency, catastrophe can threaten. Again, other accounts of autistic experience identify how common and important this in everyday experience.[28,39]

This enquiry is a first descriptive step and does not of course enable generalised inferences about autism or autistic and non-autistic experience; the sample is small and distribution of autistic and non-autistic participants not balanced. But, we consider such an approach at depth both necessary and in practice novel and informative on many of the historically described and researched phenomena thought to be intrinsic and stable characteristics of autism; such as deficits in empathy, ‘social reciprocity’, or ‘theory of mind’ and routinised behaviours.[5] The findings here suggest the possibility that these phenomena thought intrinsic parts of the autism phenotype may often be better understood as *specific states of mind dependent on specific*

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contexts. Similarly, some outcome behaviours from these conditions thought characteristic of autism may often be better seen as disjunctures from normative expectation. This highlights how differences in perspective and relevance may lead to mis-attribution in clinical theory and language[40] An implication then is that such outcomes might be at least partially mitigated if there were altered transactional settings, and some early intervention studies support this view.[41,42,43] Most commonly in our enquiry, when we expected difference, we found different levels of similarity, every time we expected to find qualitatively different outcomes, we found common processes. These we came to feel then could be interpreted as common processes found across the “Human Spectrum” but operating against different setting conditions and thus amplified into qualitative differences. Similarly, when we thought we might have uncovered some key autism-specific impairments, we found instead what could be understood as individual differences acting dynamically within varying setting conditions; this included, instead of an intrinsic lack of ability, a lack of the capacity to channel an ability into practised activity in the shared social world. A further implication for the future could be a route towards the development of a more jointly made and accepted ‘neuromixed’ language[29,44,45] for autistic phenomenology, which could reduce the issues around ‘translation’ and misunderstanding that can arise in current descriptive and clinical usage.[40] In our exploration, sometimes common usage sufficed (‘trust’, ‘burnout’); sometimes new usages seemed mutually appropriate (‘sensorium’, ‘social joining’, ‘flocking’). We are grateful to an anonymous reviewer pointing out how a lot of our findings have been foreshadowed by neurodiversity scholars and we have indicated the relevant references throughout our discussion. One of the lessons of this exercise surely is that both clinical professionals and autism researchers need to read the neurodiversity literature with care if they want to avoid continued ‘translational’ misunderstandings.

CONCLUSION

Our shared phenomenology enquiry is a first practical expression of a participatory and co-constructed approach to understanding autistic phenomenology in the context of neurodiverse and neurotypical experience.[16] As a first step, it is descriptive and cannot offer firm conclusions or solutions, but it suggests alternative theoretical, empirical and therapeutic points of view for future enquiry. For instance, from a practice perspective, it suggests that enquiry

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into deeper aspects of phenomenology and developmental experience can only be progressed through establishing a prior mutual understanding and trust between participants in phenomenological enquiry. From a theoretical perspective, it supports the idea of considering autistic experience as individual difference within a common human spectrum.[9,10] From an empirical point of view, it suggests the importance of relying as much on qualitative reports of lived experience in context, as on the quantitative data derived from normatively framed settings.[7,9] In this paper, we have begun to sketch the theoretical and therapeutic implications of such an approach, which include the need to work towards promoting positive processes such as trust, respect, and lived experience of safety (both in inter-personal and physical environments), which we suggest may be common needs across the human spectrum. This can best be accomplished by attending to the modifiable contexts that disturb them. ‘Interventions’ can then be framed as recovering the prior conditions to allow people to progress towards reciprocal sharing with others in their own way; thus re-establishing the energy to find a new common ground and allowing people on either side of a distinction border to move towards each other. Details of how such intervention practice could be constructed - including establishing trust through sensitivity to autistic states - is beyond the scope of this paper, but is something the authors intend to address separately.

Statements

Ethics

The participants in this study were the authors alone, whom all gave explicit and implicit consent for the project by taking part and writing the report. We did not consider ethical approval in these circumstances was required.

Conflicts of Interest

Jonathan Green is a UK NIHR Senior Investigator (NIHR NF-SI-0617-10168) and Trustee of the UK autism research charity Autistica. He reports funding from MRC, Wellcome, DfID, NIHR, Action for Medical Research, Rosetrees Trust, Autistica, Waterloo Foundation; Lecture Honoraria from World Association of Infant Mental Health, University of Haifa; Director’s fees from a not-for-profit PACT training company IMPACT (CiC 10902031). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

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Author contributions

Dinah Murray contributed to the conception, design, data acquisition, analysis, and interpretation of this work. She contributed to the substantive draft version of the paper. Damian Milton contributed to the conception, design, data acquisition, analysis, and interpretation of this work. He contributed to the drafting and revision of the paper and gave final approval of the version to be published. Jonathan Green contributed to the conception, design, data acquisition, analysis, and interpretation of this work. He led the drafting, revision and submission of the paper and gave final approval of the version to be published. Jo Bervoets contributed to the conception, design, data acquisition, analysis, and interpretation of this work. He contributed to the drafting and revision of the paper and gave final approval of the version to be published. Dinah Murray sadly died just after the finalization of the first full manuscript. All subsequent changes during the submission process have been made in the spirit of her contributions and have been mostly limited to the Methods section. In honor of the memory of Dinah Murray and for her initiative in getting and keeping us engaged in the project, she has been put as first author of the paper.

Data Availability

The emphasis was on spoken dialogue based on intermediate written and agreed records of the experiences by all participants. The excerpts included are from this extensive written background resource that we developed and the emphasis in the excerpts is true to these written records. These written records (including the excerpts as quoted in the paper) are available from the corresponding author based on prior agreement on maintaining privacy of the authors with respect to their contributions.

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Fig 1 – Derived Themes

Legend: Themes showing commonalities (red); Themes showing differences (green); Themes showing much overlap (blue)