

Managing an Autistic Heart

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ABSTRACT: Autism spectrum conditions represent a broad category of behavioural, cognitive and neurological atypicalities. The difficulties experienced by people on the autism spectrum with regards to their emotional awareness, regulation, expression and interpretation are often mentioned in literature – and regarded by autistic people themselves – as salient features of the condition. The primary aim of my research is to help deepen our understanding of these difficulties, in order to gain a subtler appreciation of what ‘being autistic’ actually means. An ethnographic focus on emotional experiences in autism promises to introduce a new, unique pathway toward a clearer understanding of a condition too often thought to be unintelligible. In this article, I argue that insofar as autistic people may experience difficulties in discerning, managing or communicating their emotions, these difficulties mainly stand to reflect and allude to their unique positions within a complex network of connections: social, cultural and neurological.

KEYWORDS: anthropology, autism, emotions, ethnography, neurodiversity

Introduction

Social anthropology has a rich tradition of theories on emotion. Drawing mostly on cultural particularities of emotional experience, expression and discourse, these theories tend to emphasise the socially constituted nature of emotions, as well as their cultural and historical specificity and their inherent relationality (e.g. Ahmed 2004; Lutz 1988; Reddy 2001; Wikan 1990). My own study, while it draws heavily on this disciplinary tradition, engages instead with what is a very different sort of particularity – not cultural but neurological. My goal in this article is to grapple with the challenging topic of emotions as these are experienced and understood by people on the autism spectrum. I wish to offer a perspective which could potentially expand and refine our grasp of emotional states and processes so that it accounts for the whole variety of human experience, not limited to neurotypical contexts.

This article is based on ethnographic work done with autistic adults in the U.K. While autistic people are social actors in every sense of the term, a study of their emotional experiences must emphasise the role

of their bodies, and specifically their brains, in shaping their emotional landscapes. Therefore, an analysis of emotional experiences in autistic adults – a dispersed and extremely diverse group of individuals who could be thought of as sharing a neurological, rather than a cultural alterity – calls for an approach to emotions which places brains on par with culture, focusing on the very interaction, constant and often unexpected, between social and neurological processes. In this article I aim to show that emotions can best be understood as indexes of a person’s unique position within a complex network of connections: social and cultural, yes, but also, importantly, physical, psychological and neurological.

A few words on the structure of the article. Following a brief section on method, I will go on to lay down the foundations for a discussion on emotions by briefly reviewing two influential theorists in the anthropological study of the topic. I will demonstrate why these approaches are valuable when attempting to make sense of the emotional experiences of autistic adults, but also show that these approaches, which focus mostly on social and cultural contexts, remain somewhat lacking when the object of study is a form



of neurological, rather than cultural alterity. Next, I will present a narrative by an interlocutor of mine, as well as some biographical details of hers that are valuable for understanding her narrative. I will then move on to discuss and analyse her own views and reflections regarding her emotional life. Finally, in the concluding section of the article, I hope to tie together convincingly the various arguments and evidence presented throughout, to demonstrate that insofar as autistic people may experience difficulties in discerning, managing or expressing their emotions, these difficulties mainly stand to reflect their unique positions within a complex network of social, cultural, psychological and neurological connections. But first, let me begin by addressing the question of relevance; what does autism have to do with emotions, anyway?

What Does Autism Have to Do with Emotions?

The diagnostic and social category known as autism spectrum conditions represents a very broad range of behavioural, cognitive and sensory atypicalities; yet the difficulties experienced by autistic people specifically with regards to their emotional awareness, regulation, expression and interpretation are often mentioned in literature as some of the most salient features of the condition. Examples from anthropology include Chamak et al. (2008), who in reviewing autobiographies written by autistic individuals found that ‘regarding emotional regulation, 6 subjects reported core impairments related to this domain. They described themselves as having an emotional deficit or an exaggerated emotional reactivity’ (2008: 275). This finding is consistent with those of Davidson (2007), Brownlow (2007) and Ryan and Räisänen (2008), to name a few, and is representative of countless blog posts and autobiographies. Additionally, cognitive psychologists frequently offer such statements as ‘it is well established that emotion recognition and mental state recognition are core difficulties in people with autism spectrum conditions’ (Golan and Baron-Cohen 2006: 591). Other examples include Hill et al., who argue that ‘it is commonly believed that individuals with autistic spectrum disorders (ASDs) have difficulty processing their own and other people’s emotions’ (2004: 229), and Samson et al., who found that ‘individuals with AS/HFA¹ had greater difficulties identifying and describing their emotions, with approximately two-thirds exceeding the cutoff for alexithymia²’ (2012: 659).

It may seem, therefore, that the difficulties experienced by autistic people with regards to their emotional existence is a well-established fact. However the accuracy of such statements as those brought above clearly depends to a great extent on what precisely we mean by ‘emotions’; which is, after all, ‘a polythetic concept if ever there was one’ (Beatty 2010: 430). The problem arises when very different types of processes, ruptures and challenges are uncritically placed under the umbrella of ‘difficulties with emotions’, and as a result, much of their subtle yet important nuances are concealed, and our understanding of them is inevitably impaired. In this article, then, I will suggest a framework through which the social, affective and embodied lives of autistic people can potentially be understood with more clarity and precision.

A Note on Method

This work is based on twelve months of ethnographic fieldwork. During this period, I have attended and actively participated in the regularly held meetings of two different social groups for autistic adults in two different cities within the U.K. Other fieldwork sites included autism conferences, job fairs and movie nights; as well as *Autscape* – a four-day retreat organised by and for autistic adults. During my period of fieldwork I have also volunteered at a social club for autistic adults, run by a local branch of the National Autistic Society. However, my role in this group was as a volunteer, and I did no data collection while there. In addition, I have conducted thirty face-to-face interviews with adults on the autism spectrum. The interviews – held in cafés, pubs and interviewees’ homes – were open-ended and semi-structured, and were recorded and transcribed.

My ethnographic research also included a significant portion of online data collection. I have conducted dozens of online interviews over email and Facebook. Quite a few of these interviews extended over long periods of time, often months, with dozens and even hundreds of messages exchanged. In addition, I have become a member of various Facebook groups opened by and dedicated for adults on the autism spectrum. I have also been following just under 100 blogs written by authors who identify as autistic. Consequently, I received, via RSS reader, approximately thirty relevant blog posts per day. I have saved and filed those which were most relevant, enlightening, representative or generally educational.

The ethnographic materials presented in this article are the spoken and written articulations of a single in-

terlocutor of mine. Victoria (pseudonym) and I have been in continuous engagement throughout the course of my fieldwork, and have met face-to-face on five different occasions; once for a very long interview, and four additional times in the context of a social group in which she was a member. Victoria and I have also exchanged hundreds of Facebook messages.

Caution: Emotion Talk in Progress

In her influential book *Managing Turbulent Hearts* (the title of which I borrowed for this article), Unni Wikan (1990) has assumed an outlook on emotions as primarily social processes, emergent and relational. Emotions, according to Wikan, play a mediating role between social requirements and an individual's determination to conform. And it is in this way that people's emotional lives can be said to become constitutive of morality. Catherine Lutz, on her part, in her book *Unnatural Emotions* (1988), has noted how the implicit assumptions made in Western perceptions of emotions tend to de-emphasise and conceal the important role of culture in the experience of emotion. Moreover, 'while emotions are often seen as evoked in communal life', she has argued, 'they are rarely presented as an index of social relationship rather than a sign of personal state' (1988: 4). Lutz was thus aiming to 'deconstruct an overly naturalized and rigidly bounded concept of emotion, to treat emotion as an ideological practice rather than as a thing to be discovered or an essence to be distilled' (ibid.).

Wikan's understanding of human emotions as an active, often conscious struggle to navigate social relationships and moral imperatives – and to attempt to adapt one's bodily urges with social inscriptions – will serve as the starting point for my own argument. In addition, Lutz's views of emotions as ideological practices rather than personal states, and particularly her appeal to regard emotions as indexes of social relationships, will also prove to be exceptionally instrumental. Through a careful adaptation of these two approaches to emotions, I will attempt to open up a space where the difficulties autistic people are said to experience with regard to their emotions may themselves become revealing as indexes of such individuals' own unique positions within complex networks of relationships.

Thus, once the overly general concept of 'emotional processes' is disentangled to reveal the varied workings of their assemblages, we may then begin to point to the precise whereabouts of the specific types of social links that are loose or broken, and that result in

some people being left out of the sort of 'emotion talk' that might come so naturally to others. And following this line of reasoning, instead of asking why it is difficult for autistic people to *discern* or *communicate* their emotions (thus implicitly assuming that emotions are distinct, internal and communicable 'entities'), we may ask instead: What particular parts of the social project of collectively accomplishing a mutually understood 'emotional outcome' do autistic people find difficult, are excluded from or take no interest in?

I would point out, however, that there is one distinct disadvantage to Lutz's and Wikan's views on emotions when these are considered in relation to people on the autism spectrum, whose very interaction with their surroundings is affected to a large extent by processes that are certainly *not* unequivocally social – at least not in the orthodox sense of the term. In other words, in the case of autistic people, atypical sensory processing, proprioception and cognitive functioning are every bit as vital in shaping their manner of interaction with their world, others, body, self and experience as the language they speak or the morals they possess. A focus on only those predominantly social and cultural aspects that shape emotional experience, then, when autistic people are concerned, is bound to be lacking. What is needed is a unifying approach that would position upbringing alongside hypersensitive hearing, for example, or unemployment alongside poor executive function, in order to develop a more refined model of emotions that would consider the equal effect and importance of both these crucial, albeit very different, types of components. The following narrative will hopefully help demonstrate this point.

A Saturday Morning

One Saturday evening in early spring, Victoria sat down to write the following text on a Facebook group for autistic adults in her area:

Today I woke up very happy because my daughter is staying over for the night – as she does every weekend. I look in the kitchen cupboards and realize there are only boring grown up foods and so I must go to the supermarket and buy nice things as well as fruit and juice for her to snack on. A supermarket. On a Saturday. I know only this group will understand exactly how much those words hurt my brain, but I eventually get the guts up to go.

When I am there the lights seem to flicker more harshly and the beeps are louder than the last time I went and people want to stand in the middle of aisles

and stay there. But it's ok. I get a bit too much shopping and blow the weekly budget, but I know my daughter will be happy as she is growing so fast and eats almost as much a grown man would already. I remember how this Tesco used to be a co-op years ago and my lovely late Mum would drive me there and back and we would always have a little giggle and a treat afterwards. I am thinking I miss her a lot.

I phone the taxi company and order a cab from the co-op and a lady in front of me turns and looks at me and giggles before leaving the shop. The taxi driver asks several times where I want to be picked up from and I say co-op over and over again, getting frustrated, as the beeps get louder and people stare at me. The man behind the till shakes his head and carries on making the items BEEP BEEP BEEP!

I get a phone call from my daughter's father asking where I am, he has to take his son to a party and I tell him I am still waiting for a taxi at the co-op. He tells me it is a Tesco now and then I see where I have gone wrong. I ask if he could take 5 minutes to pick me up with the shopping or I have to order another taxi. He says ok, but as he puts the phone down I can hear him say 'she's a fucking idiot that one'.

When he arrives I see he has his son in the car and our daughter, I apologize for the inconvenience but he ignores me and looks straight ahead. He drives like a maniac because he is late and angry and it is my fault and I worry we will crash or get whip lash as he screeches around corners too fast. He talks only to his son.

By now I am pouring with sweat and wanting to cry but instead I go mute and look at my hands. I take in all the shopping and tell a neurotypical friend on the phone about the co-op Tesco mix up and he says I should see the funny side because he can. But all I know is that now I need 10 minutes alone in a dark room to cry like a child because the beeps are still beeping and the lights are still buzzing and flickering and the anger is still against me from the drive, and the woman is still laughing at me in my head.

And I was so looking forward to seeing my daughter and having a giggle and a treat at home like my Mum and I used to. So instead of collapsing in my bed, I quietly get a nice plate together of lots of fruit and yogurt and snacks. My girl is now on the computer and looks at my red teary face and tells me she is not feeling very hungry anymore. Neither am I.

I suggest that what is of particular significance in this text is how social relationships, bodily sensations and flickering lights, memories, ideal outcomes and their failings, crowded supermarkets, social anxiety, hypersensitive hearing and sneering store clerks, fast moving cars, loud beeps, selective mutism, phones, fruit bowls and faces red with tears – that is, a unique com-

bination of *social, neurological and physical* processes – have all joined up to create an event experienced as meaningful in a very particular way.

But we would be mistaken to assume that this monologue, rich in nuance and detail as it may well be, could be a sufficient basis for understanding the ways in which Victoria experiences and communicates her emotions. As Beatty (2010) has posited: 'emotions are not the creation of a moment; they participate in manifold relationships formed over periods of time. Our writing, if it is to have any credibility, must reflect this complexity' (2010: 430). Indeed, we might be wary of giving the above text any more thought before we become more aware of the relevant history that preceded the events it describes. In the following section I will share those bits of Victoria's history that I believe are most illustrative of the complex and often unexpected influence that her cognitive, sensory and behavioural atypicalities have had on her social role, morals, sociality and subjectivity – and vice versa. And I wish to demonstrate the equally crucial effect of both social processes *and* neurological conditions – components that are only truly distinct in theory – on Victoria's emotional landscape. The quotes given below include extracts from our interview, informal chats and Facebook correspondence.

Fragments of a Biography

Victoria is 39 years old and single. She is the mother of a 22-year-old son and a 14-year-old daughter whom Victoria is confident is autistic, though she has not been assessed due to her father's objection. Both her children have not lived with her since her breakdown four years ago. 'I have lost my children from losing my mind and not been strong enough to get them back or save them when needed', she told me. It was this breakdown that eventually led to her being formally diagnosed with Asperger's syndrome, although she had self-diagnosed long before then. Her children live with their fathers and only stay with her on weekends.

Like so many of my interlocutors on the autism spectrum, Victoria is extremely sensitive to all sensory stimuli; unpleasant sounds and the feel of certain materials are the absolute worst, she says; but light, smell and taste can also cause extremely uncomfortable sensations. Additionally, she is said to have dyspraxia, which among other things means she repeatedly loses her balance and trips over, often hurting herself. Yet her experience of pain is somewhat unusual, she notes; she can barely feel a terrible

smack on the head; a paper cut, on the other hand, can cause excruciating pain.

Victoria is bright and intelligent, and very eloquent when she is not too nervous to speak. Despite this, she has not worked in years; she finds it intolerable to work at an office, where the constant noise hurts her ears and the everyday office gossip triggers her anxiety. She thus lives on benefits, which were lately cut in half following a debt she found herself unable to pay. As her resources quickly dwindle, she recently considered going back to work in the sex industry ('it will be web cam this time', she explained). She decided against it, however, remindful of the terrible experiences she suffered the last time she traded sex for money ('I cannot have sex with randoms ever again' she proclaimed, 'some of the men will never leave my mind and it is quite painful and shameful').

Victoria is very much a visual thinker; her mind translates every word she hears into a set of images, shapes, colours or patterns. When she hears the word 'mirror', for example, she envisions a sequence of images containing every mirror she has ever seen, playing from start till finish in the blink of an eye. The word 'really', to offer another example, appears fast-moving and green. In some respects, Victoria has a fantastic long-term memory ('Fantastic is fireworks', she once told me, translating for me her mind's visualisation back into spoken language. 'Every fireworks you've ever seen?' I asked. 'Yeah, and you can pick one', she smiled); she can remember conversations she had in verbatim, and she often plays them back in her head afterwards, as if they were a movie. She also has vivid memories ranging back to when she was only eighteen months old. At the same time, however, Victoria has very poor short-term memory, which often renders even the simplest tasks unmanageable.

Victoria had recently lost her mother who was sick with lung cancer. 'I miss her too much to bear and I know the depression I am going through at the moment is due to that', she said. 'My hair has started to fall out from stress and I blame myself for not looking after her properly before she died'. Her siblings blame her as well for not being there beside their mother at the moment of her demise. They were all taking turns to stay with her; and they were supposed to call and remind her to come when it was her turn, but they never did. 'And as it turned out', she recounted, 'Nobody was there. And that's my fault in the family ... So, they all hate me now'.

Finally, Victoria's life has been punctuated with episodes of utter disconnectedness, characterised by extreme disorientation, non-functional short-term memory, loss of speech and a loss of control over her

body. She has come to refer to these episodes as breakdowns; a commonly used – yet somewhat vaguely defined – concept in the autism community. 'Autistic people will always experience breakdowns', she explained; 'I ran away, self-harmed, screamed and shouted my way through my early years'. Particularly upsetting events, such as her mother's passing, are likely to lead to a breakdown. It takes months for her to recuperate from such an episode, and its effects – such as her children being taken away from her – are often permanent and disastrous.

Unemployment, dyspraxia, upbringing, sensory processing disorder, social exclusion, executive dysfunction. Some of these would normally be considered social factors, while others would be considered neurological. But crucially, these are never isolated components; they coincide and are in constant dynamic, and so this categorisation between what is social and what is neurological is in some ways futile. It is only the singular and emergent way in which all these various types of interlinked processes have affected Victoria's experience of herself and of others, of events, of her environment and of her body that can provide the context for us to begin to appreciate the ways in which Victoria experiences and communicates her emotions.

Emotions Are Also Objects of Reflection

Like so many of my interlocutors, Victoria considers her own emotions to have formidable force over her. During one of our early chats she wrote:

I have extremely strong inner emotions. The emotions are so strong, so overwhelming, that to show them outwardly would be a very uncomfortable experience for everyone present. I was taught from a very young age, do not cry, do not shout ... The same goes for showing love, or happiness. It can be too strong to show with mere words or actions.

When she was a child, Victoria told me, her mother had repeatedly taught her to tone down her emotional reactions, while her sisters used to mockingly parody them, deeming her behaviour embarrassing. And yet Victoria claims she is glad to have been taught to suppress these actions: 'Nobody actually wants to be that expressive, if it is to show pain. And if being happy made me "look like a spaz", I didn't want that either. The physical sensation of a tantrum is so unpleasant ... *but the knowledge of being embarrassing to everyone is a wakeup call like no other*' (my emphasis). Thus, alongside whatever aspect of her cognitive processing that led her, as a child, to exhibit her emotions atypically,

we learn that Victoria's reluctance to expose the full range of her emotions is in itself, predominantly, the product of *social norms* and *moral imperatives*. It is – to some extent, at least – the result of taking concern in other people's comfort. Of wanting to conform. Of wanting to do the right thing.

'And instantly', Victoria reflected shortly afterwards in her account that day, 'I turned my feelings inwards ... [and] after that there was no amount of finding out how I "felt". I had no idea how to express it'. Her reflection demonstrates a crucial point: emotional experience and emotional expression do not necessarily occur in separate domains. As Wikan has established in her account of the Balinese, emotions emerge in the intersection between an individual's tendencies, language and society's norms and expectations. When her way of expressing emotion was rejected by those around her, Victoria consequently lacked both the resources and the audience to articulate her emotions. Her tendencies can be said to have dissolved into mere potentialities, amorphous forces pulling in a direction opposite of society's demands, leaving her on her own devices to 'orchestrate' (Bagatell 2007) – indeed, to 'manage' (Wikan 1988) – these often contradicting forces. Understandably, she had rather limited success; hence, 'there was no amount of finding out how I "felt"'. Insofar as Victoria was describing, in this reflection, a difficulty in emotional expression, communication or discernment, she was in fact describing a much more fundamental difficulty; a struggle to negotiate moral attitudes and social expectations on the one hand with her unwitting and increasingly problematised visceral reactions on the other. Consequently, an indefinable affective turmoil *was*, in a very real sense, Victoria's 'emotion' at that time.

All this began to change when Victoria found another, less judgemental audience with which to connect on an emotional level: 'I became addicted to quiet times by myself; star gazing, enjoying the sun, enjoying the breeze, sounds, scents, touch, insects, animals, nature. Real things ... so you don't have to express your emotions in that case, because they just are.' Victoria was beginning to develop a strategy which would reconfigure the isolation caused by her perceived moral duty to refrain from communicating her emotions – and allow her to regain a sense of connectedness to the world. She was beginning to author the mantra that she still very much abides by today: emotions, she realised, seldom need to be communicated at all. Instead, they could simply be felt. 'The stars, the sun ... insects, animals, nature' have afforded her this opportunity to feel without having to put the feeling into words, body language or actions. Gradually these

connections took shape and were reinterpreted as articulations of joy, sadness, pining or grief.

By Way of Conclusion

Returning to Victoria's account of her experiences that morning, we may now approach this text with a more nuanced understanding of the events she describes. Then, we can perhaps acknowledge the full complexity of Victoria's relationship with her autistic daughter, who she conceives as having 'lost' on account of her not being strong enough to 'save'. We would appreciate her brave decision to go to the supermarket on a Saturday morning only to buy treats for her daughter, knowing the risk this posed to her well-being. We may note the significance of her pleasant memories of shopping at that supermarket with her own mother, and in light of her atypical memory, as well as her mother's recent death and the circumstances surrounding it – we may now understand why those memories were so vivid and persistent that they led her repeatedly to mistake the new supermarket for the old one. We may speculate what connotations the sneer on the face of the clerk had raised in her in light of years of hostility and exclusion she had encountered, and contemplate the full effect of her ex-partner's vicious remark on the phone. And we can appreciate why the beeping noises figured so prominently in Victoria's account: not only as recurring painful stimuli, but also as a symbol for the utter inhospitableness of the non-autistic environment which she inhabits. As we consider these factors, influences and histories, we may now begin fully to appreciate not only *why* the events that day unfolded as they did but also, importantly, what precisely about these events hit against Victoria's perception, memory, experience, morals and body to have made them meaningful in a very particular way. In other words, we may now appreciate what it was that made these events emotional.

Insofar as Victoria may experience difficulties in discerning, managing or expressing her emotions, then, these difficulties mainly stand to reflect and allude to her unique position within a complex network of connections: psychological and physical, social and neurological. It is with a nuanced appreciation of the particular characteristics and histories of Victoria's connections with her body, self, experience, others and the world around her, that we need to approach her narrative and ask what it might reveal. And it is the same awareness and sensitivity that we could and

ought to extend to other autistic people, as we try to understand what being autistic actually means.

To conclude, as we broaden our theories of emotions to consider all forms of neurological diversity, we need to move away from the implicit assumption that any valuable particularities would only be found through a focus on social and cultural differences. Humanity has many forms of diversity, social as well as neurological. We would benefit from appreciating the unique ways in which emotions actually emerge from the singular combinations of all these different components as they progress and intertwine.

Acknowledgements

This work was supported by the Wyse Fund Fieldwork Expenses Grant and the Ling Roth Writing-up Scholarship.

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Notes

1. AS – Asperger’s syndrome; HFA – high functioning autism.
2. Alexithymia is ‘a disorder of affect regulation and mediation’, according to Taylor et al. (1999: xiii).

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