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Talk for Northern Network for Medical Humanities Research Congress 2021: Narrative agency and precarity in life writing about autism

By Anna Stenning

I would like to start with two quotations which reveal two different attitudes to the precarity of autistic lives. The first comes from an educational manual about psychology that centres on the idea that it is defined by a singular cognitive deficit, an impairment in Theory of Mind. The second comes from writing by a well-known autistic individual.

> Imagine yourself along in a foreign land. As you step off the bus, the local people crowd toward you, gesticulating and shouting. Their words sound like animal cries. Their gestures mean nothing to you. Your first instinct might be to fight, to push these intruders away from you; to fly, to run away from their incomprehensible demands; or to freeze, to try and ignore the chaos around you. The world of the person with autism may be like this. (Happe 1998: 49)
>
> No, autism is not a 'gift'. For most, it is an endless fight against schools, workplaces and bullies. But, under the right circumstances, given the right adjustments, it CAN be a superpower – (Thunberg 2019)

Autism is often described in terms of precarity, sadness or tragedy, and this is also often seen as a unique opportunity for a story. While this may to occasions for autistic people to narrative their experiences, as demonstrated by the huge corpus of autistic life writing, in broader narratemes autism is used as an excuse for the relatively empowered to reaffirm their assumed normality. And while precarity is often understood to mean temporary economic conditions or job security over which we have little control, it can also be connected to our shared 'vulnerability' that is a fact of our mortal existence (Lipenga 2020).

However, stories about autism in the tragic mode use autism as a figure for a heightened form of bodily fragility or vulnerability, without due attention to the economic and cultural contexts that contribute to the difficulties that autistic people and their families experience. While acknowledging the biological and genetic origins of autism and the fact that many autistic people (not limited to those who have formal diagnoses) experience co-occurring conditions that do threaten flourishing, I would argue that our individualistic and limiting concepts of what it means to be human exacerbate the difficulties many autistic individuals experience, including people with higher support needs. Diagnosis for autistic people is the gateway to support, but it is also the potential source of stigma and dehumanising interventions such as ABA, along with a search for eliminating autistic genes before we understand what autism means at the level of the individual person.

The dominant cultural framework that sees human value determined by verbal prowess and dominance over an individual's material surroundings, and this is used to justify an ethics of 'cure' or demeaning behavioural modification for autistic people and, historically, others who are deemed 'socially deviant'. A more accurate picture would show that autistic people have the potential to flourish when given the right support, but this perspective requires a shift in paradigm, rather than more data. I would argue that autistic people and others who rely on support are not necessarily more ‘precarious’ when appropriate support is available, but certainly more aware of our shared material precarity, even if voicing that is taboo. My aim in my current project is to consider the cultural barriers to considering autistic individuals’ stories about their experiences and ethical commitments.

In doctoral thesis on narrative agency, the political theorist Sara Lucas considered what happens when we don’t recognise people as agents, ‘where being an agent means both being constituted by an impossibly complex matrix of stories and having any number of stories of one’s own to tell.’ This means that we tend to see people as either overcoming their difficulties or failing due to bad luck, as ‘choosers or losers’ rather than as ‘beset *both* by the capacity to act and factors that limit this capacity to act. This cultural ‘narrateme’ means that, even when our intentions are benign, we ignore the fac that choosing to see others in terms of a ‘single story’ is itself an exercise of power (Lucas).

Lucas recalled an anecdote reported by the Nigerian novelist Chimamanda Ngozi Adichie. In a TED talk from 2009, Adiche talked about her early experiences of her childhood family servant, who was a young man called Fide. She recalls how one day, Fide showed her a basked his brother had made, and she had been shocked that someone so disadvantaged, and dependent on others for material support, was able to make something so beautiful. When Adichie moved to the US to attend a university, she described how found her room-mate was shocked that she had perfect English and a like for American music. For Adiche, this echoed her own misrecognition of Fide’s ‘story’, since for the roommate, ‘there was no possibility of Africans being similar to her in any way, no possibility of feelings more complex than pity, no possibility of a connection as human equals’ (reference Adichie).

Lucas concluded that this is an example of where the subject is deprived of narrative agency due to dominant cultural scripts about what people who share a characteristic are like, but this is not only a problem at the level of society or culture but at the level of individuals and our responsibilities to each other. This is because to harbour this kind of defining narrative, even when one’s intentions are benign, is to contribute to the systematic misrecognition of the subject of that narrative. The point is that each of us is guilty of misrecognition, no matter who we are.

Misrecognition at this level has direct consequences for social justice, since it reinforces existing structural imbalances. Lucas believes that this can be ameliorated by granting ‘narrative agency’ to human subjects, and this emerges both through broader contexts of association (such as this panel) and through our ability to interpret our own and other people’s experiences. This means that the much-discussed idea of narrative identity, adopted in life writing studies, must be seen as secondary to a much more complicated process of everyday storytelling (Lucas 2016:).

This idea of agency at odds with medical models of autism, which, as Greg Hollin has argued, posit agency as a property of autism (or autistic brains) rather than of individual persons and the relationships in which they live their lives. This compounds with the fact that our most culturally privileged method of communication - fast-paced verbal speech - is often difficult for autistic people. Many definitive cultural narratives about autism continue to posit autism as an abject existence, defined by an absence of self-awareness and intersubjective engagement, even as there is growing recognition of the heterogeneity of the condition. The desire to find a single ‘cognitive mechanism’ underpinning autism which is reproduced by those who are already in positions of power reinforces stories about individuals in ‘the tragic mode’ but it also contributes to harm to autistic people. It also misdirects collective attention to situations in which difficulties or pleasures arise – such as Thunberg’s difficulties at school, or the autistic person who experiences sensory overwhelm in a noisy urban environment but thrives in collective autistic spaces, at in the natural environment.

I argue that granting agency to autistic authors to narrate their lives may show us more about what it means to be human as we face challenges but also opportunities for joy and shared flourishing. As Ralph Savarese has argued, literature is an important tool for generating recognition and respect across differences in body-minds, and this can create new forms of ‘neurocosmopolitanism’ that decentre the assumption that there is just one ‘ideal’ way to be human (Savarese and Zunshine 2014; see also Walker, 2021).

I am interested in what both life writing and ‘everyday narrative exchange’, on its own or through assistive technology, may contribute to individual and collective sense making about autism, specifically as we develop new languages and cultural frameworks, such as the neurodiversity paradigm. And while all such scripts risk being co-opted into capitalist economic production, contextualised readings of such works as they suggest new possibilities for ‘association’ and ‘recognition’ across different cultures.

This means that recognising the socio-cultural origins of autistic precarity requires ‘entering into the sphere of action, or exercising one’s political agency’, which is only really possible with ‘confidence that one will appear in the world and be recognised by others as a unique being’ (Lucas 2016). Stories of cognitive modules or genetic predictors will not by themselves help us identify what it means to be an ‘individual’ person living a life the real world.

Life writing by autistic authors can therefore be seen as rhetorical acts of generative potential that exist in and through existing networks of stories. The ‘precarious’ cultural status of autistic life texts – means that they are often seen as a direct transcription of experiences, rather than recognised as rhetorical/creative acts. I am concerned that what counts as objective knowledge in certain fields – which is replicability, rather than other possibilities such as ‘trained sight’ - does not allow room for individual such acts of recognition (Lucas 2016). It is only through nuanced readings based on the – rather than ‘big data’ or generalised approaches, that we grant narrative agency to autistic individuals. Yet, individual acts of literary interpretation – which have previously been part of scholarship in many fields – are seen as 'too subjective’ to offer anything valuable to scholarship.

As a neurodivergent person myself, I have an ‘insider’ perspective on the potential harms posed by misrecognition, and I see this as an important part of considering the ‘hidden’ aspects of medical understandings of autism. But I am aware that, as I comment on work that has occurred in earlier fields, I contribute to my own precarity as an academic who steps outside of established hierarchies between disciplines and ways of measuring research quality. While funding bodies and universities are trying to create structures to show recognition of the value of ‘diversity’, ethical review, grant and publication review bodies are not yet able to support such work, since the draw on the expertise of established researchers. It is seen as ‘risky’ to coproduce research with those we have traditionally thought of as more dependent than us.

Yet, the ‘misrecognition’ of autistic life texts – as in, that they are not regarded, in the fullest sense, as creative acts - has fueled my current research and recognition that I should not try to see my life in terms of a ‘single story’ told by others. This would not be possible, however, without the collective knowledge and experiences autistic people and others who find themselves unable to ‘perform normality’. From them, I have developed new language and stories to narrate atypical experiences. This leads me to believe that, if there is to be a ‘medical’ study of autism, we must begin to measure research on autism in terms of real-world experiences beyond the university, rather than just following ‘business as usual’. Rather than focusing on the established psychological, or even parental, gaze, there must be the possibility of trained sight informed by autistic people’s experiences.

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