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On representing autism and the altruism of self-reflexive writing

Abstract:

Autoethnographic stories about illness and disability are usually written for, and with, readers in mind, engaging in the 'reciprocity that is storytelling [whereby] the teller offers herself as a guide to the other's self-formation' (Frank 1995: 17–8). While self-reflexive narratives can be immensely healing for the writer, they also invite readers to reflect upon the issues at hand and bring about a shift in their own thinking. As such, self-reflexive writing can be a powerful tool for advocacy and for challenging the status quo. By allowing readers to empathise and connect with the subject matter at a very personal level, it can illuminate nuanced moments of adversity or insight, and capture a depth of understanding that more traditional texts may not always depict. This article draws on interviews with families living with high functioning autism and the exemplar text *Far from the tree: Parents, children and the search for identity* (Solomon 2014). Following Solomon, the article's author reflects upon personal experiences and embraces self-reflexivity as a way of better understanding herself, representing her subjects, and helping to illuminate a common theme that difference is a value worth nurturing.

Biographical note:

Katie Sutherland is a Doctoral Candidate at Western Sydney University's Writing and Society Research Centre. Her Doctorate of Creative Arts research project is entitled 'Painting the spectrum: everyday stories of families living with high functioning autism'. She is interested in the use of personal writing as a platform for connection and advocacy. Katie is a teacher and freelance journalist, published across a variety of Australian newspapers and magazines.

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> All literature asks the same question: What does it mean to be human?
> (Yanagihara 2016)

When Liesel[1] sat her oral exams for a degree in Operatic Performance, she requested the examiners move her to a larger room. With acutely sensitive hearing, she could not distinguish the pianist's notes in the smaller room. Rather, she could hear all of the accompanying harmonics, making it impossible to focus. She also had difficulty breathing in the confined space, and therefore, difficulty singing. Thankfully, Liesel had developed an awareness of her needs over time and could articulate these to her examiners, who kindly obliged. Now, some years on, with no shortage of mezzo-soprano roles, she has not only graduated with Bachelor and Post Graduate degrees but has applied for a scholarship to study her Masters in Opera in Germany and Italy.

This is in stark contrast to the vision a school careers guidance officer had of Liesel when he told her at age fourteen that she would never go to university. She had just been diagnosed with Asperger's syndrome (also known as high functioning autism), she was a 'Goth' and was regularly getting detention at school for truancy and misbehaviour. 'I have to admit that I was a total rat-bag', she muses.

> School was a really difficult time. I didn't understand the other kids and they didn't understand me. So I just rebelled. I would have meltdowns and become very down. Things got a lot better when I changed schools and went to a performing arts college with likeminded kids. There, we were expected to take responsibility for our own actions. We weren't reprimanded for not turning up to class; it just meant that we didn't learn. And by that stage I was engaged enough with the lessons that I wanted to learn (Interview, 18 April 2016).

Liesel's mother Susan describes a precocious and willful child. 'She wasn't always as delightful as she is now', Susan laughs. It wasn't until Liesel's diagnosis that Susan knew what she was grappling with so 'Life got so much easier because my expectations were put in sync with Liesel's processing skills. I also learnt to understand triggers and to keep the stress levels down'. Susan now realises all five of her adult children are probably somewhere on the autism spectrum (as well as her ex-husband). Each one of them is immensely artistic, three of them classically trained in music. Two of Susan's grandchildren have also been diagnosed with high functioning autism. 'They are such individual, talented, wonderful people that I don't quite know how I would have coped with kids who weren't on the spectrum', she states. 'A lot of parents think it's the worst thing that ever happened to me, but in actual fact it's not. I just love their individuality and creativity' (Interview, 3 May 2016).

When I speak with Susan, I connect with her story, as I too am a mother of a child with high functioning autism. I empathise with Susan, as she shines a light into the dark corners of her lived experience, and I feel less isolated in the knowledge that she understands my situation. As I listen to Susan, I imagine myself with not just one, but five children on the spectrum. I gaze back and forth from her story to mine, broadening my understanding and eventually resting in the knowledge that while every story is unique, the stories of others provide pause for constructive reflection. I feel a sense of empathy too when listening to Liesel, my eyes welling with tears when she tells me about the difficulty of her school years. I flinch and worry that my son will experience such hardships, but I do not turn away from that discomfort. Instead, I willingly allow myself to become immersed in the richness of Liesel's experiences. I consciously observe my reactions and subsequently face my fears, while also clinging to 'Liesel the success story' and the hope that my son too will find his way.

Interviews with subjects, such as Susan and Liesel, form a collection of narratives I am currently writing about families living with high functioning autism. Throughout this paper, I will draw on the stories of those I have interviewed, as well as my own. Utilising an autoethnographic methodological framework in my research, I am 'connecting the autobiographical with the ethnographic to tell stories that are informed by and help make sense of lives in cultural context' (Boylorn and Orbe 2014: 17). Employing a mindfulness of sorts, I observe my reactions when I interview my subjects and write their stories, intertwining my experiences with theirs, my story with their stories. In autoethnography, such introspection is actively drawn upon as a source of rich data to extend an understanding, and to open up critical engagement with readers about a societal phenomenon (Wall 2006; Holman Jones, Adams and Ellis 2013; Bochner 2013). Unlike some more traditional forms of social inquiry, autoethnography embraces self-reflexivity and subjectivity in an effort to elucidate the nuances of real people and real lives (Wall 2006). This article, subsequently, examines how self-reflexive writing on illness and disability, namely high functioning autism, can capture a depth of understanding that more objective texts may not depict. It considers how looking inward can serve to be a form of altruism, with connection at its core. It also investigates how self-reflexive writing can be a powerful tool for challenging the status quo and showing that difference is a value worth nurturing.

The sense of connection

Humans are social beings, and just as isolation can be detrimental to our health and wellbeing, connection can be healing (Cacioppo and Patrick 2008). Here, I theorise that such social connection can be garnered from stories through narrative empathy, allowing us to become part of a community (Keen 2006; Frank 1995). In *The Wounded Storyteller*, Arthur W. Frank (1995) writes of the reciprocal bonds that are created between storyteller and listener. 'These bonds expand as the stories [of illness and disability] are retold. Those who listened then tell others and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller are not separate but are different aspects of the same figure' (xii). As well as forging connections, stories help us to understand our realities. As author Susan Sontag notes: 'Story – the idea that events happen in a specific causal order – is both the way we see the world and what interests us most about it' (2007: 220). Through an exchange of stories, tellers and listeners can piece together a mosaic of experiences giving meaning to the big picture of daily life (Mattingly and Garro 2000). Particularly for people experiencing illness or disability, the connection and understanding that comes from stories can hold much gravitas.

Illness narrative

Illness and disability are written about in many ways. Examples include medical records written in a clinical setting by health care professionals, journal articles by researchers, magazine and newspaper articles, biographies, memoirs, blogs and fiction. While some forms of writing emphasise the biological factors of illness or disability, others relate lived experience. While some are objective, others are subjective (Richards 2008). All are ‘illness narratives’. The emerging field of narrative medicine proposes that patients can only be properly cared for when they can share their illness story with a doctor (Solomon 2016). The doctor will have the patient describe their pain in autobiographical terms, rather than relying on a purely physical examination. Arthur Kleinman argues that such narratives are critical because an illness is more than a physical manifestation. Rather, it is about the person as a whole, their suffering, and how that person copes with the experience. He writes: ‘Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability’ (1988: 3). He explains that beyond physical pain, illness problems can manifest as frustration, anger, relationship difficulties, confusion, insecurity, unemployment shame and ‘dangerously declining self-esteem’ (4). The same could be said of people with a disability, or their carers. Furthermore, people may face stigma, the societal habit of turning illness or disability into something mysterious, usually something negative (Sontag 1991). In his book, *Neurotribes* (2015), a detailed history of autism, journalist Steve Silberman notes how autism was thought to be the result of toxic parenting for several decades. He writes of the irreparable damage this caused to individuals and their families:

> By blaming parents for inadvertently causing their children’s autism, [psychiatrist] Kanner made his syndrome a source of shame and stigma for families worldwide while sending autism research off in the wrong direction for decades’ (2015: 188).

Stigma still exists around autism in varying degrees today.

Like Kleinman, philosophy scholar Havi Carel decrees that traditional physiological descriptions of illness are insufficient in capturing the entire picture, with ‘phenomenology’ offering a more comprehensive perspective. She describes the ‘physical, psychological and social’ (2008: 12) aspects of illness, citing phenomenologist Merleau-Ponty, who proposes that humans are by definition ‘embodied and enworlded’ (13). Carel describes how Merleau-Ponty responded to philosopher René Descartes, who ‘defined us as thinking, abstract souls who temporarily and contingently occupy a physical body’ (20). Merleau-Ponty, on the other hand, focuses on the ‘inseparability of mind and body, of thinking and perceiving’ (21). In the case of high-functioning autism, the waters are further muddied because of its ‘invisibility’, with symptoms sometimes only noticeable to the most experienced eye (Autism Spectrum Australia 2013). Challenges for people on the spectrum are primarily social and behavioural, often mistaken for negative personality traits. Some individuals may also experience learning difficulties, dyspraxia, ADHD, depression and epilepsy (Attwood 2007). Here, I draw on Simon Baron Cohen’s: ‘Autism is both a disability and a difference. We need to find ways of alleviating the disability while respecting and valuing the difference' (qtd. in Solomon 2014: 280).

Lived experience

Take Louis for example, one of the subjects in my collection of narratives. Now 12 years old, he was diagnosed with Asperger's when he was a baby. His mother, Catherine, a preschool teacher, noticed his quirks very early on, having read on the topic when her nephew was diagnosed a year earlier. A striking-looking young man with an olive complexion and jet-black hair, Louis maintains eye contact when he speaks. He appears engaged and genuinely interested, asking questions about my home city of Sydney and talking about his school camp to Uluru and Canberra. Such conversation is quite remarkable for any boy fast approaching adolescence. I certainly would never guess he was on the autism spectrum. In fact, when he bids me farewell with 'have a lovely day', I wonder in what way this charming boy is possibly disabled, as he seems to have everything going for him. He has even chosen the university in Sydney that he wants to attend once he leaves school. With an encyclopaedic knowledge of all things to do with natural disasters, he plans to study volcanology. 'He could talk about natural disasters until the cows come home', says Catherine.

> He started borrowing books on volcanoes from the school library when he was in kindergarten. The librarian said if you're sick of them we'll put a stop to it. But I said she should go for it. If he's interested in it let him read everything about it' (Interview, 14 November 2015).

I notice a swelling pride when Catherine speaks to me about her eldest son. But while Louis' knowledge can spawn hours of adult conversation, other children are only prepared to listen to so much. When I ask Catherine if Louis has any close friends she answers, 'No, not really', and behind her radiant positivity, I detect a hint of sadness. Children on the autism spectrum have a notoriously difficult time making friends. Reading social cues, facial expressions and body language do not come intuitively (Attwood 2007).

'I think it was hardest when he was probably four or five and he'd walk into a social situation and everyone would roll their eyes and go "here comes Louis"', Catherine told me.

> He was oblivious I think, but it would break my heart. Absolutely break my heart. He gets sad and at times as he really wants friends, but it's so difficult for him. He doesn't understand boys the same age and they don't get him. He will probably never really fit in until he's in university and he's with like-minded people (Interview, 14 November 2015).

Through telling her story, Catherine highlights the nuances of parenting a child on the spectrum; the pride, joy and sadness. As I retell her narrative, I reflect on my own experience and emotions, while also pondering what makes disability and what makes difference – indeed, something I contemplate each and every day. Author and scholar Andrew Solomon has explored such terrain within his writing on why some people are less accepted in society than others. His book, *Far from the tree* (2014), is a sociological study of 'families who accept their children, and how that relates to those children's self-acceptance – a universal struggle we negotiate partly through the minds of others' (26). Solomon states that difference can happen to anyone at any time and elucidates this not only through his exhaustive collection of narratives (he conducted some 300 interviews for the book) but by also drawing on his personal struggles with difference; with homosexuality, dyslexia and depression. He comprehensively explores the blurred line between illness and identity, writing: 'It's clear that identity is a finite concept. What's not clear is the location of its boundaries' (34). He questions whether autism, for example, is just another way of being, or whether it is an illness that should be cured or avoided. Within this conundrum are even more shades of grey. Parents of a severely autistic child, for example, may struggle to accept that this is just an identity issue, as compared to the parents of a child with high functioning autism. Silberman further explores this, arguing that autism, like homosexuality, constitutes just one aspect of humanity. He proposes that autism could simply be a cognitive difference, suggesting a broader model for acceptance of 'neurodiversity'. The neurodiversity movement, Silberman notes, does not look for causes or cures, or 'framing autism as a contemporary aberration' (2015: 470). Instead, history tells us that autism has always existed. He writes: 'Whatever autism is, it is not a unique product of modern civilization. It is a strange gift from our deep past, passed down through millions of years of evolution' (470). The neurodiversity movement advocates that the way forward is to help families and individuals lead happier, healthier, productive lives – by moving away from stigma and negativity (Silberman 2015). Until, however, we have enough information to understand – and to help us to this understanding – we use stereotypes and metaphors (Sontag 1991).

Illness or identity

In *Far from the tree*, Solomon reflects on how the destigmatisation of homosexuality has led him to lead a full and happy life, and applies this reflexivity to his interviewees, questioning whether some of the disabilities and conditions he writes about, including autism, are cause for alarm. He considers the evolution of illness to identity and what this means in the context of the families in his book:

> I thought if gayness, an identity, could grow out of homosexuality, an illness, and deafness, an identity, could grow out of deafness, an illness, and dwarfism, an identity, could emerge from an apparent disability, then there must be many other categories in this awkward interstitial territory. It was a radicalising insight (4).

When Solomon was born in 1963, homosexual activity was criminal and throughout his childhood it was considered an illness. When he was two, *Time* magazine reported homosexuality as 'a pathetic little second-rate substitute for reality, a pitiable flight from life' and a 'pernicious sickness' (Solomon 2014: 15). He writes with great honesty of his coming to terms with his homosexuality despite his parents' desperation to 'cure' him of it, the confusion over his sexuality as a teenager, and subsequent thoughts of suicide. In an article in *The Guardian*, Solomon notes:

> The exploration of the philosophical complexity that lies between sickness and health is perhaps the most urgent matter facing medicine and literature, because definitions of illness often run up against humanist definitions of identity. I know whereof I speak: I have an identity that was long deemed an illness … When we define an illness, we have a grave effect on those who are subject to it (2016: 8).

He discusses how iconic homosexuals such as Oscar Wilde and many other less prominent gay people were brought up to think of themselves as ‘diseased to the very core, and so we lost much of their brilliance and their joy’ (8).

In *Far from the Tree,* Solomon is startled to find himself aligned to the communities he researches. He reflects that just as his parents wanted to cure him of homosexuality, his likely response to having a deaf child would be ‘to do whatever he could to fix the abnormality’ (2014: 3). Upon conducting further research, however, he speaks to members of Deaf culture who view their difference not as a deficit, but as an identity. Solomon questions his initial line of thinking and subsequently starts to see himself as part of a larger group: ‘Having always imagined myself in a fairly slim minority, I suddenly saw that I was in a vast company. Difference unites us’ (4). Through writing with reflexivity, he admits his own shortcomings, challenging his own assumptions and prejudices. He similarly reflects on the need for ambivalence in parenting, allowing readers opportune relief from the manuals that promote the ‘perfect parent’ or the ‘perfect child’. Autoethnographers Keith Berry and Chris J. Patti note that an expression of ambivalence demonstrates ‘something special to reflexive storytelling, that is, something intrinsic to the telling of stories from which others can learn and grow’ (2015: 268). By reflecting on the theme of ambivalence and exposing their doubts and contradictions, by divulging their fears and failures and those of their subjects, authors can illuminate the complexities of human nature and show we are all fallible.

Solomon further elucidates the nuances of life through intersecting and juxtaposing his identity as a gay man, with his dyslexia and depression. To him, dyslexia and depression are illnesses, while being gay is an identity. He is thankful to his mother for helping him overcome his difficulties with reading and writing, and he chooses to take medication for his depression. This exploration of personal choice around what to fix and what to accept is a common thread throughout his book, as Solomon draws on personal anecdotes and reflects on how other people come to terms with their situations. Subsequently, the autoethnographic journey of research and writing delivers profound personal rewards:

> Writing this book addressed a sadness within me and – somewhat to my surprise – has largely cured it. The best way to get through these horizontalities is to find coherence, and in the wake of these stories, I recast my own narrative (45).

As a ‘wounded storyteller’, Solomon becomes a ‘wounded healer’. Through his story, and the stories of others, Solomon forges an empathic bond with his readers, and the ‘circle of shared experience widens’ (Frank 1995: xii).

Community gardens

When Juliet's son Gabriel was diagnosed with Asperger's as a six-year-old, she had very little support. Her friends had never heard of the condition, her husband refused to accept the diagnosis, and all she knew of autism was the film starring Dustin Hoffman, *Rain Man* (Levinson 1988). Even Gabriel's schoolteachers were naïve as this was the early 2000s and diagnoses were in their relative infancy. Asperger's syndrome was officially recognised by the American Psychiatric Association when it published its fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) in 1994 (Attwood 2007). Gabriel was struggling to fit in at school, and he was quickly attracting the label of 'naughty boy'. The kindergarten teacher approached Juliet halfway through the year at pick-up time in the playground and blurted out: 'Is he pulling my leg or does he have a problem?' Juliet recalls that 'She didn't choose to make an appointment, or speak to me earlier in the year about his behaviour, or take me aside to a private place to go through some of the behaviours she was observing. She automatically assumed he was a naughty boy' (all quotes, Interview, 30 April 2015). The teacher's comments were not only confronting, they were also unhelpful. 'The school couldn't give me any leads', she explains. 'Well what do I do now I thought? Where do I go? It was like, he's got a problem, we don't know what it is, we'll just leave that with you and you go and find someone to identify it. Bye, see you later, with no support and definitely no emotional support'.

While coming to terms with the eventual diagnosis, Juliet did what she had done in the past and turned to her passion for gardening. She had always used gardens for relaxation and sensed that they could also be a respite tool for Gabriel. With a spade, a pitchfork and thankfully, the school's backing, she began work on transforming the gardens around the school into a living chill-out zone. Quickly earning the respect of other parents, Juliet planted daffodils and sunflowers, fruit and vegetables and paved winding pathways through to secret green hideaways. She grew shady trees and brought in chairs for children to sit amid nature, away from the noise and activity of the schoolyard. She created artworks in the form of mosaics and signs about the plants so children could learn more about the plants and the environment. She started a tree-planting day and a buddy system where younger children were paired with an older child on a garden project, a program that still exists in the school today.

'When Gabriel interacted with his buddy, it was the first time he actually understood why you would want to relate to other children', says Juliet. While she didn't realise it at the time, she was developing a therapeutic environment that had a flow on effect for Gabriel's learning in the classroom, and for other children's learning too.

> The connection to peace and tranquillity, to tactile experiences like clay or earth, I wanted for Gabriel. Having worked as an art teacher, I knew how art helped small children make the transition into a different learning environment, going from play to sitting and paying attention and not touching and not wriggling. Like art, gardens provide that different setting for learning and a place to just be. And as I later found out, art and gardens are spot on for kids on the spectrum. Of course, not only did the garden help Gabriel, but a host of other children too. Adults enjoy the garden too and it continues to be used today.

Juliet went on to set up gardens, places of tranquility, at other schools, including Gabriel's high school, a public school with a class for children with autism. What started as a form of personal therapy soon turned into a project enjoyed by numerous other families. Without a network to turn to, she created a place for others to come. But the first step, she says, was finding strength within yourself. 'A strong parent will find a way', Juliet muses. 'You can have different support networks but unless you are strong within yourself, unless you can see the path clearly, or even slightly clearly, then you're not going to move forward. You can't rely on schools for direction, or for therapy for that matter. First, you have to get yourself in a better place. And then you can help others to find their way'.

Like Solomon, Juliet has become a 'wounded healer' (Frank 1995). Through her garden and her story, she has managed to simultaneously negotiate her unique situation, while creating an inviting place for others to ponder, rest and reflect, myself included. The retelling of her story invites further reflection and healing. As Arthur Frank (1995) writes: 'Telling stories in postmodern times, and perhaps in all times, attempts to change one's own life by affecting the lives of others' (18).

Conclusion

The fundamental paradox of self-reflexive writing is that while it is most definitely inward looking, helping a writer to work out their changing identity, it can also be a powerful platform for helping others, for generating awareness and for advocacy. Through storytelling's mutuality, writers and readers of self-reflexive narratives on illness and disability access a unique connectivity. Shared stories of ordinary lives, of the messiness and chaos of the everyday, show that we are all capable of fallibility and most of us of resilience. These stories can, moreover, illuminate moments of adversity and show that difference is human, not to be feared or stigmatised. Beyond that, such narratives can represent social justice and prompt affirmative action or, as Solomon calls it, a 'rethinking of humanity' (2014: 45).

Endnote

1. Names of all interviewees have been changed to protect their privacy.

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