

About Falling Apart and Trusting the Process: Snapshots from the Life (and Work) of an Academic with ADHD

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Abstract

In this essay, I give an autophenomenographical account of what it is like for me to be late-diagnosed with ADHD while in the process of writing my dissertation. I explain how ADHD is an invisible disability and how little help is offered when the medication does not work. I explore how, because of my ADHD, my brain is at the same time my most valuable resource/tool and my worst enemy. I describe the various challenges in my life, psychological as well as physical, and call for academic institutions to provide structures that allow for non-normative temporalities and ways of doing research. In this essay, I offer some snapshots of my own experiences in the hope that neurodivergent students and scholars will see themselves reflected (and accepted), as opposed to an academic article *about* neurodivergents written by a neurotypical scholar.

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The year before I got my ADHD diagnosis, at age forty-one, I attended a conference in Sweden. I already suspected that I had ADHD, but I did not yet know the vocabulary and did not fully understand how it affected me. During a panel at the conference, in which the audience had to sit still and either listen to audio or watch a video, I experienced what I now know is termed 'sensory overload' (Thank you, Neurodivergent Twitter!). I think the audience was supposed to become immersed in the experience and perhaps feel relaxed. The sounds awoke a sort of core of anxiousness in my chest, and I kept looking at the door, trying to figure out an escape route. I could not leave without disturbing everyone else, and I did not want to disrespect the presenter, so I just sat there and let the waves of discomfort roll over me. In my memory of the experience, the lights were out during the presentation, so I could not distract myself from my thoughts or calm myself down by embroidering, something that often helps me sit still and focus during lectures, meetings, and so on. I offer this account as an example of how ADHD is often an invisible disability – there may be a storm of emotions and thoughts raging on the inside, but people cannot necessarily tell, especially if the person with ADHD has become used to masking it and has learned to disregard their own emotions and physical sensations in order to blend in or as a defense against being called 'difficult' or 'dramatic'.

After the panel, lunch was served in the university cafeteria. I needed to be alone, so I avoided people I knew and sat down at an empty table, hoping that everyone would stay away. For me, ADHD does not look or feel the same every day – sometimes I am a social butterfly and enjoy mingling and meeting new people, but on other days I am afraid to answer my phone, I may avoid eye contact, I become unable to speak ('selective mutism'), and might become so overwhelmed that I have to leave a situation or event in order to prevent a meltdown. In the cafeteria, on that day, I was trying to soothe myself after having experienced sensory overload (I am very sensitive to sounds, smells, light, and physical sensations in general – it often feels like I am being attacked by

outside forces (especially during my period)). The cafeteria became more and more crowded, and strangers sat down next to me. I just looked at my food and tried to create a solitary and quiet space for myself amidst all the chatting. The chair opposite me was still unoccupied, and I really wanted it to remain empty, so that I could avoid small talk.

When conversations are superficial, I find it hard to pretend that I am interested, and I often start yawning, which is embarrassing, because it makes me feel like an impatient and self-centered child. Emotional dysregulation is pronounced when it comes to my ADHD. I cry easily, and for most of my life I have tried hard to suppress these feelings, the display of which has often been viewed by others as 'inappropriate'. During oral exams, I have experienced being affected by students' emotions. For instance, if students are so nervous or disappointed that they cry, I cry with them, and if they get excited because of a good grade and cry tears of joy, I also cry with them. I remember an examiner who told me that my tears were unprofessional, and another colleague who once told me that I would have to learn to control my emotions. Before I started doing research on death and trauma and attending conferences on these topics (especially the Queer Death Studies Network events), I felt (even more) out of place in academia; I never understood why there was no space for emotions in the Humanities, when so many of us read and analyzed works of literature that were meant to provoke feelings in the reader. If there was no space for emotions, there was no space for 'the real me'. My crying made me feel like a failure, and it fit into the narrative I have been fed all my life: that I was at the same time 'too much' and 'not enough'. I have become more gentle with myself, though, and I am in the process of allowing myself to show my emotions.

But let us return to the conference in Sweden and the empty chair at the lunch table. Eventually, the cafeteria became so crowded that someone sat down. I did not know this person. I think I may have nodded a "Hello". I went to get some coffee, and when I sat down again the silence started to feel awkward, so I made a comment about the coffee. The other person responded, and before I knew

it, I started talking about how much I dreaded situations such as this, where I might end up having to talk to strangers and trying to avoid small talk. They responded that they felt the same, and we soon started talking about family estrangement. They recognized me as 'the poet' who had read a poem about my estranged mother the previous night at a reception. Small talk drains my energy, but having deep (often dark) conversations about personal trauma and emotions invigorates me. At one point in the conversation, my new friend mentioned that they had ADHD, and I understood why I found it so easy to talk to this person I had just met. I told them I suspected that I also had ADHD, and we started comparing struggles. For the first time in my life, I felt safe being my 'authentic self' in public, and I learned how important it is for me to be around other neurodivergent people. I have always felt 'odd' and out of place – always on the outside of the circle and never inside. I have tried to fit in and have longed to be part of a community, but I have instinctually felt that people sensed there was something 'off' about me.

I have always read this rejection as a sign that I was somehow 'wrong'. After I got my diagnosis and read more about ADHD, I started to see past events through a different lens. 'Being lazy' was translated into having 'executive dysfunction', for instance. I have talked to other ADHD persons about the exhausting process that begins after diagnosis. It feels like falling apart; I became aware of how much other people had shamed me for struggling with various aspects of adult life and how I had internalized this shame. I grieved for the child I once was, who did not get the help she needed so that she could function well in school. I have always gotten good grades (in the subjects I found interesting), but I found it hard to concentrate when doing my homework, either because the world around me was too distracting, or because random thoughts made me lose focus. I also could not sleep at night, so I often overslept. I do not fit the stereotypical image of the (white) cisgender boy with ADHD who disrupts the classroom; my ADHD tends to create noise inside my mind, and my inability to sit still (which I tried to counter in school by drawing during classes) is

manifested through a constant switching between tasks – getting up from my desk to go do something in the kitchen, for instance. I now see how ADHD has affected almost every aspect of my life.

When I got my diagnosis, I had just entered the third (and last) year of my PhD fellowship; during the writing of my dissertation, I started to suspect that I was neurodivergent. I have always struggled with insomnia and have found eating to be a challenge. I thought I had an eating disorder, but I could never see myself reflected in any of the descriptions of eating disorders. I suffer from nausea, often accompanied by migraines (triggered by sensory overload), which makes it hard for me to eat. The lack of sleep and sustenance, of course, impairs my ability to function and focus. When speaking of these struggles, I am often met with the response that "Everyone experiences this from time to time". However, people with ADHD are challenged in ways that often wreck their lives. My ADHD means that I live in a world governed by contrasts; for instance, I am either unable to concentrate, or I am so (hyper)focused on something that I tend to stop listening to my body's signals (hunger, for example). I have seen other persons with ADHD point out that our inability to focus on one specific task is often caused by hypervigilance (also a symptom linked with childhood trauma), which means that we are unable to stop paying attention to *everything* that is happening around us. Thus, while I am trying to read a text, I am perhaps also hyper-aware of noises from the street outside, smells from within the home, light coming through the window, and so on. I find it easier to write at night (sometimes until the sun comes up), because the world is quiet(er). This, of course, messes up my circadian rhythm. Which affects my ability to eat. Which affects my ability to sleep.

I keep thinking of one specific phrase in the evaluation of my Master's thesis from 2008, in which my supervisor wrote that I had structured the chapters of my thesis, which was awarded the highest grade possible, in an 'unusual' manner. I still have no idea what she meant, and I was afraid to ask her, because then she would find out that I did not know what I was doing, and that I did not belong in academia. When writing my dissertation,

I was unable to follow the instructions of my supervisors, such as providing an outline for my study. I felt that I was letting them down, and that I was a failure, because I could not fulfill such seemingly simple tasks. I lost focus and started 'chasing shiny objects' in the form of new ideas – first, I wanted to include embroidery in my dissertation (it is now an important part of my study), and since I often have no concept of time, I thought that I could not only finish the embroidery (which is a slow process) but also make a short film about it. One of the benefits of having an ADHD brain is the creativity and the ability to come up with original solutions, but my ideas often cause me to lose focus. I have learned that my writing happens instinctually; I often experience an amazing creative flow and work on multiple parts of my dissertation at the same time. I somehow master this chaos, but it does require more time than more traditional ways of doing research. It took me two years to write my Master's thesis, which was supposed to take only a year. I started working on my dissertation in October 2017, and I am now way past the deadline. I got sidetracked along the way – by three deaths (my estranged mother, my beloved grandfather, and my cat Sookie), a custody case, a new relationship, and my diagnosis. As the collective of researchers behind the 2015 article "For Slow Scholarship: A Feminist Politics of Resistance through Collective Action in the Neoliberal University" write, "Sometimes life gets in the way [of doing academia]" (Mountz et al. 2015, 1244). My personal experience with ADHD is that I struggle with the everyday aspects and tasks of life and this affects my ability to work. When "life gets in the way" for me, I am already struggling with sleep deprivation, an inability to control intrusive thoughts, food issues, and an impaired memory, for example, because of my ADHD.

I had hoped that medication would help me manage the more severe symptoms of my ADHD. My psychiatrist prescribed Ritalin. I wrote sixty pages of my dissertation in two weeks, during the summer holidays, when my daughter was at her father's. I had never experienced being able to focus like that, but I felt completely stoned at the same time (like I had smoked a lot of pot). I also

experienced symptoms of depression; I remember walking through the city with tears streaming down my face and not knowing why I was crying. I tried two other types of ADHD medication, but the side effects were too severe: I felt dizzy, I lost my appetite, I was fatigued, and I lost the ability to concentrate on reading. The medications ruined the last six months of my fellowship. I went on sick leave for a month to recover from the havoc done to my mind and my body and to deal with the disappointment that the medication did not work. My psychiatrist had nothing else to offer me. She could not recommend a therapist who specialized in neurodivergence (I have since found one, who is very good but also very expensive). I was put on a waiting list for a course on 'Life Skills for People with ADHD' offered by the municipality. I had no idea where or how to get help, other than doing a self-study on ADHD (which was hard to do, when I also had to finish writing my dissertation) and becoming a part of the online community for neurodivergents on Twitter (which has been incredibly helpful). I bought books on ADHD, but I still have not had time to read them. I had to focus on developing the skills to get back to writing my dissertation. I have found out that performing tasks in intervals of thirty minutes usually works, although sometimes I am too antsy to sit down. I focus on working *with* my ADHD (which I have been doing for most of my life without being aware of it) instead of *against* it.

I have developed strategies for quieting or distracting my mind; for example, I watch series (currently *Star Trek: Deep Space 9*) on my iPad when performing practical tasks, such as cooking and cleaning, so that my mind does not get lost in negative thoughts. I have become vocal about how physical spaces can be made less stressful for me: I ask students to refrain from wearing perfume to class, since perfume often triggers my migraines and nausea, and I insist on eating indoors at restaurants, because sitting in the sun hurts my eyes (and can cause a migraine). I have found out that I have auditory processing disorder, which makes it difficult for me to process oral communication and to distinguish between sounds in noisy environments (for instance when I am having a

conversation with someone, and people around us are also engaged in conversations). Subtitles make it easier for my ears and my brain to communicate. I talk to my students about my ADHD and share the various strategies I have developed to get work done. I do this to counter the stigma that is still attached to ADHD and to be a positive role model for neurodivergent students.

When I was disappointed that the medication did not work, my supervisor reminded me that every time I had done a presentation on my dissertation, including my pre-defense, I had done exceptionally well, and he pointed out that I had made it this far in my career without ADHD medication. I realized that perhaps I had not been granted the fellowship *despite* my ADHD but *because of* my ADHD and my creativity and ability to think differently. I thought of Ann Cvetkovich's idea, in *Depression: A Public Feeling* (2012), of "resting in sadness" (14), which helped me through the process of mourning after my estranged mother's death a few years ago. This idea, along with doing needlework, showed me the importance of taking time, of slowing down, and of paying attention to emotions and sensations. I realized that in order for me to return to and finish my dissertation, I would have to 'trust the process' – my process, my way of working. So that is where I am at right now; I will hand in my dissertation, but I have to accept that it will take time, because I also need to deal with life and figure out how to function in a neurotypical world as a person with ADHD.

When reading about the concepts of Slow Scholarship and 'patient writing', as explored by Jenny Helin, Nina Kivinen, and Allison Pullen in "Until the Dust Settles: Pasts, Presents and Futures of Critical Publishing" (2021), I saw my own way of doing research reflected. I started thinking that perhaps these calls for forms of scholarship that prioritize allowing research to develop in a more organic way, directly challenging the product-oriented temporality governing the neoliberal university, also (indirectly) call for academia to make room for disabled scholars who might, for various reasons, require more time to do their research. My ADHD has me switching between two forms of temporalities; it sort of feels like existing

outside of 'normative time', because I experience time as moving either very slowly or very fast. Concurrently, I also tend to do things very slowly or very quickly. It might take me hours to bathe and get dressed (and years and years to write a dissertation), because I get distracted, but I also tend to read and process information quickly. I alternate between days of high activity and days where I have to prioritize resting. In "But You Don't Look Disabled": Non-visible Disabilities, Disclosure and Being an 'Insider' in Disability Research and 'Other' in the Disability Movement and Academia" (2020), Elisabeth Griffiths also calls for a different temporality in academia: "Much of what people experience around disability in academia is hidden for fear of stigma and the perception of not being able to 'keep up'. I want to feel welcomed and understood in academia, so that on the days when I cannot 'hyper-perform' then it is OK to say 'no more today', without it affecting my ambitions, prospects, collegiality or sense of self" (126). "[C]ollectively slowing down as an act of resistance in neoliberal academia", as suggested by Helin, Kivinen, and Pullen (2021, 106), and centering care and patience in the ways we (re)create working environments, would lead to better conditions for scholars with various disabilities.

Mountz et al. stress "the benefits of unexpected 'disruptions' in the research and writing process" (2015, 1238). My dissertation has grown from my periods of sick leave, which allowed me to examine grief and trauma from a different angle and caused my research and my life to 'bleed into each other'. I have struggled with accepting that I have missed multiple deadlines for handing in my dissertation. I have felt like a failure, even though I am still working on it and I still take pleasure in writing about my subject. I find comfort in reading Jack Halberstam's assertion, in *The Queer Art of Failure* (2011), that "failing, losing, forgetting, unmaking, undoing, unbecoming, not knowing may in fact offer more creative, more cooperative, more surprising ways of being in the world" (2-3). Halberstam does not write about neurodivergence, but I do pick up a neurodivergent vibe in the introduction to the book ("failing, losing, forgetting" sums up many aspects of my life with ADHD).

When Halberstam suggests that “failure allows us to escape the punishing norms that discipline behavior and manage human development with the goal of delivering us from unruly childhoods to orderly and predictable adulthoods” (3), I see myself dancing through the text, as both an unruly child and an unruly adult, whose survival, as a human being and as a scholar, depends on the rejection of systems and institutions that require me

to ‘perform normativity’ in order to be successful, according to standards I cannot live up to. ‘Trusting the process’ will get me to the finish line, but in my own time.

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