CANADIAN JOURNAL OF AUTISM EQUITY
REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

Experiential Commentary

THE CANADIAN JOURNAL OF AUTISM EQUITY

LA REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

VOLUME 5 | ISSUE 1 | APRIL 2025

What's in a Name? A story of two diagnoses, and why the words we use matter when it comes to mental health

McKenna Hart, Independent Author, Canada

RECOMMENDED CITATION: Hart, M. (2025). What's in a Name? A story of two diagnoses, and why the words we use matter when it comes to mental health. *The Canadian Journal of Autism Equity*, *5*(1), 43–50.

CANADIAN JOURNAL OF AUTISM EQUITY
REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

What's in a Name? A story of two diagnoses, and why the words we use matter when it comes to mental health

De l'importance d'un nom : l'histoire de deux diagnostics, et pourquoi les mots importent lorsqu'on parle de santé mentale

McKenna Hart[1]

Abstract

This essay reflects on my mental health journey that began when I first received a diagnosis of bipolar II disorder at age 18. After countless ineffective treatments and conflicting diagnoses over the course of my young adult years, by the time I was 23, I feared that my condition would never improve. However, a family members' autism diagnosis prompted me to pursue an assessment myself. After two years on a waitlist, I received a diagnosis of Level 1 Autism Spectrum Disorder, which changed my perception of myself and led to a massively improved quality of life. This transformative experience showed me the importance of informed and compassionate care, and the need for a more nuanced understanding of mental health conditions and the language used to describe them.

Keywords

Misdiagnosis, bipolar disorder, autism, identity, inclusive nomenclature

Resumé

Cet essai est une réflexion sur mon parcours de santé mentale qui a commencé lorsque j'ai d'abord reçu un diagnostic de trouble bipolaire II à 18 ans. Après d'innombrables traitements inefficaces et des diagnostics contradictoires au cours de mes années de jeune adulte, je craignais, à 23 ans, que mon état ne s'améliore jamais. Cependant, le diagnostic d'autisme d'un membre de ma famille m'a incité à procéder moi-même à une évaluation. Après deux ans sur une liste

---

[1] Independent author

d’attente, j’ai reçu un diagnostic de trouble du spectre de l’autisme de niveau 1, ce qui a changé ma perception de moi-même et m’a permis d’améliorer considérablement ma qualité de vie. Cette expérience transformatrice m’a montré l’importance d’une prise en charge informée et compatissante, ainsi que la nécessité d’une compréhension plus nuancée des troubles mentaux et du langage utilisé pour les décrire.

Mots-clés
Erreur de diagnostic, trouble bipolaire, autisme, identité, nomenclature inclusive

What do you call an 18-year-old girl who shows up to the Emergency Room covered in her own blood?

Bipolar II with mixed features. At least that’s what doctors started calling me after I’d spent less than 24 hours in the in-patient mental health unit at my local hospital. The diagnosis came from a psychiatrist I had never met before and never saw again, who sat behind a desk in the small, white, uncomfortably lit room. Before I could begin to unpack what that meant, I was escorted out of the one-way doors of the psych ward with a pamphlet, a prescription, and a loaded new label.

When it comes to medicine, a proper diagnosis can be the difference between life and death. But mine didn't help me much. Even while taking a handful of medications, I couldn't go more than a few months without having an ‘episode’. Sometimes that meant I couldn't get out of bed for a week or was plagued by anxiety attacks that left me feeling disconnected from my body. Other times I would go days without sleeping and become hypersensitive to even the smallest of noises. But no matter what kind of episode it was, they all ended the same: in an uncomfortable room, answering uncomfortable questions.

To make things more confusing, every mental health professional I met had a different opinion as to why I wasn't getting better, and the diagnoses piled up, each one accompanied by a new prescription with new side effects. By the time I was 23, I was the most medicated and most miserable I had ever been in my life. I felt broken—the kind of broken that couldn't be fixed.

Around the same time, a close family member of mine was struggling with his mental health as well. His diagnosis? Autism. One day, I accompanied him to a doctor's appointment, and as I listened to the psychiatrist explain his condition, I noticed how different the experience was from what I was accustomed to. While the two of us shared many of the same symptoms, like mood and energy fluctuations, here they were described much differently. According to this doctor, his instability was the result of a dysregulated nervous system. His brain was different, not disordered. Perhaps most notably, he needed care, not to be cured.

And so, I asked my family doctor to be reassessed, this time by a developmental disability specialist, and I was put on a two-year waitlist. As I waited, I became very curious about understanding the labels used in mental health and the system at large. The more I learned about the diagnostic criteria for different disorders, the more I found that they had in common. I also began to understand all the many ways the system can fall short, and who is most likely to be affected by that.

To start, accessing mental health care in Canada is not easy. “People have to wait a long time to get mental health support,” says Dr. Yona Lunsky, the director of a leading neurodevelopmental disability research and education center in Toronto, “and the more people who are waiting means that the people who finally do get services are worse off than they would have been had they received care earlier" (personal communication[2], April 26, 2024).

Even for those who are able to access care, the extent to which the system is overwhelmed can also impact the accuracy of assessment. "It's important for a psychiatrist or clinician to listen to their patient and not rush into a diagnosis," notes Dr. Pushpal Desarkar, a psychiatrist and scientist at the same clinic. "Because of the shortage of psychiatrists in Ontario and Canada, it's typically very busy, so one reason could be that they really may not have enough time to listen to all of this nuanced detail" (P Desarkar, personal communication[3], April 29, 2024).

This nuanced detail is critical when it comes to diagnosing mental health conditions. While the standard Diagnostic and Statistical Manual for Mental Disorders (the DSM-5-TR) (American Psychiatric Association, 2013) contains detailed descriptions and diagnostic criteria for hundreds of conditions, diagnoses are largely determined by the interpretation of the clinician. "We don't have any lab tests, so it really depends on the skill of the psychiatrist", explains Desarkar. However, because there is no clear-cut understanding of the brain mechanisms that cause these disorders, even the most experienced psychiatrists can make mistakes. Desarkar says that even in specialty clinics, psychiatric misdiagnosis rates can reach up to 70% (personal communication, April 29, 2024).

To further complicate things, mental health conditions are often co-occurring, and share overlapping symptoms, making them even more difficult to accurately diagnose and treat. "Sometimes people do go through a process of having different diagnoses given to

---

[2] All quotes from Dr. Yona Lunsky are from a video interview conducted on April 26, 2024. Contributions were approved by Lunsky prior to publication.

[3] All quotes from Dr. Pushpal Desarkar are from a phone interview conducted on April 29, 2024. Contributions were approved by Desarkar prior to publication.

them," says Lunsky. "It takes some time to unpack and recognize what else is really going on, and it has to do with the expertise of the people and what they are familiar with." (personal communication, April 29, 2024).

While neurodevelopmental disorders are typically diagnosed in childhood (Zwaigenbaum et al., 2019), an increasing number of adults are seeking a diagnosis later in life (Levine 2024). At the clinic he works at, Desarkar remarks that approximately 8 out of 10 adult patients receive an autism diagnosis (personal communication, April 29, 2024). Many of these patients are women—a group that up until recently has been under-represented due to a historically male model of autism.

In fact, according to Desarkar, only about 20% of autistic women receive their diagnosis before age 18. Instead, they often first receive another diagnosis such as bipolar disorder or borderline personality disorder in their young adulthood. These assessments are often made by doctors who observe behaviors such as self-harming but fail to investigate the reasons why. "They don't get to the bottom of why autistic girls and women are cutting", he says. "They tend to miss the forest for the trees, going for the diagnosis they know." (P Desarkar, personal communication, April 29, 2024).

And so the question remained: could I be part of the 80% that was missed?

After waiting nearly two years, I finally had a date for my assessment. Before the assessment date, I had been asked to provide supplemental documents from my development in my early years, and as I read through old report cards, I found myself overwhelmed with emotion. For so long my identity had been wrapped up in words like ‘manic’ and ‘unstable’, but before I was any of those things I was ‘expressive’and ‘sensitive’. It was then that I realized just how much of myself I had learned to repress for the sake of fitting in.

Finally, the day of my assessment arrived. This time it took place virtually from the comfort of my own home, with two psychiatrists who specialized in autism. I braced myself for the typical uncomfortable prodding, but instead, I was surprised that they were most curious about things I had never talked about, like my encyclopedic knowledge of Transformers and my difficulty making friends as a teenager. By the time the assessment ended nearly four hours later, we had walked through my entire life. Two weeks later, I was told that I fit the criteria for Level 1 Autism Spectrum Disorder.

When I received my diagnosis I burst into tears. For so many years, I accepted the label ‘bipolar’ because it was the only word that came close to describing how different I felt, yet I often felt reduced to it, particularly by those who were meant to be providing care. For the first time, I wasn't being told that I was sick, or that I needed to be medicated to fit in with the rest of the world. Instead, I was being validated that my brain was wired differently, and that was okay. My formal diagnosis felt like permission to be myself, and that changed everything.

And so, under the supervision of my psychiatrist, I stopped taking mood stabilizers and instead started seeing a therapist who specialized in autism to develop strategies to manage my mood and triggers. Instead of relying on Benzodiazepines to soothe my anxiety, I prioritized creating a lifestyle that was comfortable from a sensory perspective. Perhaps the most meaningful change was in the attitude of my health care providers, who emphasized supporting my needs rather than suppressing my differences.

Now, having gone more than two years without a mood episode, it might be fair for me to say I was misdiagnosed the first time around, that my ‘depressive’ episodes could be explained by autistic burnout, and my ‘manic’ episodes the result of an overstimulated nervous system. But my symptoms did not change, only the attitude towards my care. The fact that I was given so many different diagnoses in the first place has made me wonder, could all these psychiatric conditions be more related than we realize?

Understanding these ‘neurophysiological underpinnings’ is a significant part of what Dr. Desarkar has dedicated his research to. “Unless we talk about certain dementias we do not have any 100% worked out biological model for any of our psychiatric conditions,” he notes (personal communication, April 29, 2024). Therefore, it is possible that the way we classify these conditions may change as we learn more about the underlying mechanisms that cause them. For example, Asperger’s Disorder was once a separate diagnosis given to describe an autistic person with low support needs, but was removed in the most recent version of the DSM in favour of the more inclusive label of ‘Autism Spectrum Disorder’.

“How we define a condition, how we measure a condition is always changing,” explains Lunsky. “We all try to follow the guide and then we realize that the guide isn't meeting our needs exactly, or is not quite right, so then we go through some efforts to change it”. When thinking about the future of mental health, Lunsky would like to see a ‘learning system’, which would adapt as we better understand these conditions (personal communication, April 26, 2024).

It may be a while before we truly understand the physiology of mental health conditions, but one thing we do get to decide is the way we describe them. Desarkar notes that while autism is technically described as a disorder, that term is rarely used in his practice. When it comes to the words we use, he emphasizes the importance of including the perspectives of those with lived experience. “This is the best way to learn from each other, and create a more inclusive nomenclature system,” he says (personal communication, April 29, 2024).

As someone who has been assigned many labels over the years, I believe this is a crucial first step. Perhaps the words we use right now are simply our best attempt at describing something that we can't fully grasp yet, but my experience has shown me that it's not necessary to fully understand these conditions to provide more effective care. Instead, it starts with compassion and acceptance that is reflected in the language we use. Through my autism diagnosis, I gained a new vocabulary to describe my experience. I went from being crazy to misunderstood, from disordered to different, from a problem to a person.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. (5th Edition). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Levine, H. (2024, December 3). *Autism: The challenges and opportunities of an adult diagnosis*. Harvard Health. https://www.health.harvard.edu/mind-and-mood/autism-the-challenges-and-opportunities-of-an-adult-diagnosis

Zwaigenbaum, L., Brian, J. A., & Ip, A. (2019). Early detection for autism spectrum disorder in young children. *Paediatrics & Child Health*, *24*(7), 424–432. https://doi.org/10.1093/pch/pxz119