



PROJECT MUSE®

Review of Metagnosis : Revelatory Narratives of Health and Identity

Dana Howard

Kennedy Institute of Ethics Journal, Volume 32, Number 1, March 2022,
pp. E-1-E-8 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/ken.2022.0006>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/852740>

Book Reviews

Review of *Metagnosis: Revelatory Narratives of Health and Identity*

Reviewed by Dana Howard

Danielle Spencer's book, "Metagnosis: Revelatory Narratives of Health and Identity," does many things. It is a work of autotheory, putting Spencer's own embodied narrative in constant conversation with the testimony of others along with a remarkably diverse set of critical and theoretical approaches. In the book, Spencer coins a new term, "metagnosis", which occurs when one is newly diagnosed in adulthood with a lifelong condition. The book explores Spencer's own metagnostic experience involving her eyesight along with chronicling the experiences of others to highlight the ways in which newfound knowledge of a diagnosis can in itself transform us.

Born with strabismus—"misaligned eyes," Spencer is practiced at negotiating the meaning of having a non-normative visual experience and presentation. For the most part, growing up with the condition and frequently subjected to medical attention because of it, Spencer remained largely unconcerned about whether or not she saw differently. But, as the book chronicles, in adulthood, after enduring subpar medical treatment and a series of frustrating surgeries, Spencer is additionally diagnosed with a different visual field condition, homonymous hemianopia, that was likely sustained in infancy, but which up until the diagnosis neither she nor her various doctors had detected.

Spencer describes how she discovers in her orthoptist's office that she can see only half of the visual world of each eye. This discovery leads to a deep ambivalence on Spencer's part—which includes feelings of physical vulnerability, shame that the condition had gone unnoticed for so long, as well as relief for not having to suffer through the stigma and exclusion that may have come with the additional medical diagnosis in childhood. It also leads to a theoretical examination of the limited narrative and theoretical resources that avail us in trying to make sense of such revelatory experiences and the frustrating inexplicability that such transformative experiences can have for others. This intimate narrative approach democratizes theory. As Spencer says near the end of the book,

“[k]nowledge is not simply illuminated, but is itself profoundly informed by our way of looking.” [306] *Metagnosis* invites us to inhabit Spencer’s own way of looking as she engages in critical theoretical analysis of the epistemic and practical stakes related to medical diagnosis and other identity altering revelatory discoveries.

The book is also a work of profound interdisciplinary engagement, bridging conversations happening across siloed academic and cultural spaces. The book draws widely and creatively from biomedicine, medical humanities, philosophy, disability studies, cultural studies, literature, film, oral history, and personal narrative. Ultimately, Spencer argues that metagnosis, the experience, “is largely *about* navigating different forms of knowledge.” [20] The book critically interrogates the insights growing out of multiple disciplines with respect and attention; each of these disciplines is treated as a possible source of knowledge, albeit fallible and incomplete. It will be an important resource for readers from multiple perspectives.

Finally, the book is responding to a kind of epistemic injustice, that is, to a systemic and distinctive wrong done to people in their capacity as knowers and inquirers.¹ Specifically, the book habituates us as readers to attend to and work towards mitigating the hermeneutical injustice we (and others) may face as biomedical subjects—that is, as people to be diagnosed. Hermeneutical injustice, a term popularized by Miranda Fricker and critically developed by theorists like José Medina, Luvell Anderson, and Kristie Dotson, is the phenomenon where a person is unfairly disadvantaged in their capacities to make sense of their own experience.² Hermeneutical injustice happens when certain stories remain untold, not merely because people are systemically excluded from and discredited within the collective discursive community, but also because - as a result of this exclusion and discredit - people lack the shared language to actually tell their stories in a way that makes sense to them.

At its core, the book’s project is to identify and provide a new shared language. The book offers us the narrative resources needed to make sense of a distinctive kind of diagnostic experience that has heretofore remained conceptually obscure and personally isolating. In naming the experience of metagnosis, Spencer writes, “we open a space for communalization, recognition, and critique.” [37] As a bioethicist by way of political and feminist philosophy, it is this last kind of engagement that I will focus on in the rest of this review.

So what is metagnosis? At its most abstract, metagnosis describes “any retrospective revelation pertinent to one’s identity.” [3] In the medical

context, metagnosis can take place in two ways. First, it can occur when one is newly diagnosed with a long-standing condition that has remained undetected by the individual and by medical professionals, such as learning about one's infertility or one's colorblindness. Second, it can occur when one is newly diagnosed with a long-standing condition not because the "symptoms" had gone unnoticed, but because they were only recently treated *as* symptoms due to shifts in the "the diagnostic boundaries themselves." [4] An example of this second form of metagnosis that is richly explored in the book is comedian Hannah Gadsby's experience being diagnosed with Autism in adulthood.

It is helpful to tease out three co-constituents of the phenomenon of metagnosis. First, metagnosis is experienced as a revelation, not as a fabrication. Through metagnosis, one comes to attend to an existing feature of one's own embodied life. Second, the revelation is retrospective; what is revealed is a long-standing condition, not some new physical change in one's somatic experience onset by some recent event. One's somatic experiences may change as one turns one's attention towards certain features of embodiment that would have remained unnoticed without the new diagnosis. But the event that precipitates these somatic changes is the diagnosis itself. Third, metagnosis is a revelation that is pertinent to one's identity. Not all medical diagnoses, even novel diagnoses of long-standing conditions, inform one's identity, and the transformative impact of a medical diagnosis may be highly contingent and vary by person.³ Metagnosis is meant to capture the experiences where a medical revelation has the power to rupture our sense of self and drives us to renegotiate how to move forward in the world given our somewhat altered social position.

These three features combine to articulate simultaneously the bewildering power that medical classification can have on us as well as the peripheral and limited nature of these biomedical distinctions. As for the power, nothing about us changes physically, but the newly revealed diagnosis can change our identity. It is the "knowledge that is transformative" [180]. As for the exposed limits of diagnosis, upon metagnosis we realize this condition has always been there in plain sight of the medical experts and they missed it and we have carried on.

So how does the idea of metagnosis do any work to counteract epistemic injustice on Spencer's account? Spencer rightly clarifies that hermeneutical injustice does not necessarily lie in the fact that one has lived one's life in the absence of diagnosis. She recognizes that some people experience a metagnosis as a result of lacking access to quality medical care or

attention; however, she points out that many people “wish to remain unseen by the medical gaze” and seek acknowledgement of their embodied lives in communities outside of biomedicine, which is often “associated with stigma and diminished agency.” [38] Rather, the epistemic injustice toward which Spencer focuses our attention, and which requires response, is the “elision of the experience and implications of metagnosis itself... for those who confront the phenomenon have generally not had a sound hermeneutical space in which to tell and understand their stories.” [38]

The kind of elision of experience that Spencer has in mind is strikingly illustrated in her own story of revelatory diagnosis and how difficult it was to explain her newly discovered condition to even those who knew her well and were trying to be supportive. She describes one particularly frustrating interaction with a close friend. Given the absence of any recent change in her visual experience and the lack of any discernable effect of this condition on Spencer’s behavior and activity, her friend not only struggled to acknowledge the importance that this new visual diagnosis could have for Spencer’s self-understanding; more fundamentally, he couldn’t even bring himself to accept the biomedical evidence of the reality of this diagnosis—he refused to believe that she was really “half-blind”. Her friend’s rejection of both the importance and the reality of the new diagnosis illustrates what Spencer understands as the main challenge of metagnosis: if it is the noneventness of the diagnosis that can transform us, how can we begin to explain this transformation to others or even to ourselves?

At one point, as a strategy to deal with the perplexity that resulted in her describing her newly discovered condition to others, Spencer decides to stop trying to explain or explore the particulars of homonymous hemianopia. “Instead, I became interested in trying to account for this difficulty in accounting. Both to satisfy my own curiosity, and...to attempt to communalize the experience—this time, Reader, with you.” [115] There is a conspiratorial tone to Spencer’s writing. By generating for us a language from which to engage in conversations that were previously unavailable to us, she not only vindicates the experiences many have had with these sorts of retrospective revelations, she also provides for us a call to action or at least a call to conversation. With this newfound language, we can be invited to communalize what may seem like deeply personal and isolated events.

This is an effective strategy; as I was reading the book, I couldn’t help but start seeing metagnosis everywhere and felt compelled to talk about

it with others. Over a bonfire this summer, I explained the idea to a friend and she shared a story of her own revelatory diagnosis. For a long time, she was diagnosed with asthma, but her treatment did not seem effective. Recently, after a set of frustrating specialist appointments, she found out that she had been misdiagnosed all these years - a phenomenon that may happen to up to a third of asthma patients⁴ - and was instead diagnosed with Vocal Cord Dysfunction [VCD]. It is worth focusing on the details of the nature of VCD for a bit and on my friend's experience with the diagnosis to highlight a potential concern that I have with Spencer's account.

The prevalence of VCD remains unknown, but it is suggested that cases are undercounted in clinical practice. This is in part due to the fact that VCD was initially only thought to exist in the context of psychological illness, particularly when describing "hysterical women."⁵ However, in the past few decades, researchers have discovered that the condition affects a much broader patient base, with higher incidents among women, who remain misdiagnosed and improperly treated for years, incurring unnecessary medical cost and morbidities.⁶ My friend's doctor described the prototypical patient with VCD to be young, female, and driven.⁷ The etiology of the condition is unclear, but VCD episodes can be triggered by stress or high intensity exercise. Thus VCD treatment is very different from asthma treatment and involves multimodal interventions that centrally feature speech and behavior therapy. Moreover, clinical guidelines note difficulty in identifying the condition in patients. Given its episodic nature, clinicians in part rely on the testimony of patients about the severity and experience of the episodes to identify cases. Given the population with the highest prevalence of the condition, it is thus not surprising that past names for VCD have included, "facetious asthma", "Munchausen's stridor", and "emotional laryngeal wheezing."

Although the symptoms of VCD did not go unnoticed by my friend (she was after all seeking out specialists to relieve her of breathing difficulties), the significance of her symptoms and what they potentially said about her identity remained inscrutable. My friend's ordeal thus seems very much akin to the second type of metagnosis that Spencer outlines, where recent shifts in diagnostic boundaries - from viewing VCD as afflicting "hysterical women" to a larger population, particularly "highly competitive and success oriented" women - lead to revelatory self-knowledge. Like in many of the narratives chronicled in the book, news of this diagnosis was met with some ambivalence on the part of my friend. She was relieved, not

only because the new diagnosis opened up the opportunity for effective treatment, but also because the new diagnosis clarified things to her in a deeper way. On the other hand, it was also not lost on my friend how gender, testimonial injustice, and mental health stigma have slowed research and clinical practice related to VCD and thus obscured this diagnosis for so many for so long. Both perspectives featured centrally in her story. So it seems that the diagnosis of VCD presented itself as an instance of metagnosis insofar as it was experienced “as a rupture in our habitual ways of categorizing ourselves and our experience.” [251] My friend saw herself as newly inducted in the VCD club, historically undertreated and dismissed, and now feels the mandate to share her revelation with other friends, especially if they are young women, in case they too fit the bill.

The revelatory power of VCD for my friend mirrors some of the features of Hannah Gadsby’s adult diagnosis of Autism, which Spencer examines compassionately at the end of the book. Spencer suggests that Gadsby’s performances in *Douglas* and *Nanette* can serve as exemplary models for how to productively use revelatory diagnoses as opportunities to renegotiate our identities in relation to how we are medically categorized. Surprisingly, at the close of her examination into Gadsby’s work, Spencer writes, “Ultimately, I propose, *all diagnosis can and should be metagnosis*, such metafictional diagnosis will help us to move past the often all-too-reductive realism of biomedicine, illuminating its naming authority and questioning its exclusivity.” [307]

While I appreciate the importance of moving away from biomedicine’s exclusive claim to epistemic authority in the realm of diagnosis, I am skeptical about the proposal that all diagnosis can and should be metagnosis. First, saying that all diagnosis should be metagnosis seems to undermine the distinctive nature of the experience that is so forcefully explored in the book. I worry that expanding the concept may undermine its usefulness and galvanizing power to those who have experienced such revelatory transformations.

Second, if we pay attention to the material and social conditions that give rise to metagnosis, we should at least be wary of universalizing the experience. While it need not be the case, it will likely be the case more often than not that metagnostic experiences grow out of situations in which people have had to deal with sustained and systemic medical mistreatment or inattention. This seems to be true of the three cases highlighted in this review. Spencer’s visual field revelation, my friend’s diagnosis of VCD, and Gadsby’s autism diagnosis all likely were in part the result of inattentive or

subpar medical treatment. While not highlighted in the book's discussion of Hannah Gadsby's performance of *Douglas*, there is a moment in the show in which Gadsby articulates the way in which gendered stereotypes accompanying autism make diagnosis more elusive: "My issue was I didn't understand enough about autism to understand how I could have autism. Because what we popularly understand autism to be is just something that only affects young boys that like maths a lot. And, to this day, neither of those things apply to me."⁸ Not only are these stereotypes salient for those subject to diagnosis, they are also pervasive amongst clinicians, leading to an elevated risk of underdiagnosis or late diagnosis for girls who meet the criteria for autism spectrum disorder.⁹

As Spencer makes clear, early diagnosis is not necessarily advantageous without access to social and biomedical support. However, adult diagnosis of a long-standing condition, especially if this is more prevalent in minoritized populations, is evidence that something systemic has gone wrong in biomedicine. We should be sensitive to the fact that metagnosias are often the result of some combination of medical racism, sexism, classism, fatphobia, and ableism. The idea of metagnosias can provide for us important generalizable lessons for how to go about negotiating our social identities and conceptions of health without everyone having to undergo a metagnostic rupture themselves.

NOTES

1. Fricker, Miranda. *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press, 2007.
2. Medina, José. *The epistemology of resistance: Gender and racial oppression, epistemic injustice, and the social imagination*. Oxford University Press, 2013. P. 91. Dotson, Kristie. "A cautionary tale: On limiting epistemic oppression." *Frontiers: A Journal of Women Studies* 33.1 (2012): 24-47. Anderson, Luvele. «Hermeneutical impasses.» *philosophical topics* 45.2 (2017): 1-19.
3. Barnes, Elizabeth. "Social identities and transformative experience." *Res Philosophica* (2015).
4. Aaron, Shawn D., et al. "Reevaluation of diagnosis in adults with physician-diagnosed asthma." *Jama* 317.3 (2017): 269-279.
5. Dunn, N.M., Katial, R.K. & Hoyte, F.C.L. Vocal cord dysfunction: a review. *asthma res and pract* 1, 9 (2015). <https://doi.org/10.1186/s40733-015-0009-z>
6. Traister, Russell S., Merritt L. Fajt, and Andrej A. Petrov. "The morbidity and cost of vocal cord dysfunction misdiagnosed as asthma." *Allergy Asthma Proc.* Vol. 37. No. 2. 2016.

- 7.
8. Hannah Gadsby “Douglas” (2019)
9. Loomes, Rachel, Laura Hull, and William Polmear Locke Mandy. “What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis.” *Journal of the American Academy of Child & Adolescent Psychiatry* 56.6 (2017): 466-474.