METAGNOSIS

REVELATORY NARRATIVES OF HEALTH AND IDENTITY

DANIELLE SPENCER

Bridging memoir with key concepts in narratology, philosophy and history of medicine, and disability studies, this book identifies and names the phenomenon of *metagnosis*: the experience of learning in adulthood of a longstanding condition. It can occur when the condition has remained undetected (e.g. colorblindness) and/or when the diagnostic categories themselves have shifted (e.g. ADHD). More broadly, it can occur with unexpected revelations bearing upon selfhood, such as surprising genetic test results. Though this phenomenon has received relatively scant attention, learning of an unknown condition is often a significant and bewildering revelation, one that subverts narrative expectations and customary categories.

Beginning with Spencer's own experience, the book explores the issues raised by metagnosis, from communicability to narrative intelligibility to different ways of seeing. Next, it traces the distinctive metagnostic narrative arc through the stages of recognition, subversion, and renegotiation, discussing this trajectory in light of a range of metagnostic experiences—from *Blade Runner* to real-world mid-life diagnoses. Finally, it situates metagnosis in relation to genetic revelations and the broader discourses concerning identity. Spencer proposes that better understanding metagnosis will not simply aid those

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directly affected, but will serve as a bellwether for how we will *all* navigate advancing biomedical and genomic knowledge, and how we may fruitfully interrogate the very notion of identity.

Photo: Catalina Kulczar

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PREFACE

In the mid-1980s, David Byrne, Talking Heads frontman, donned the iconic Big Suit, which transformed him from a slender figure into a large beige linen cuboid. As you can experience in the 1984 concert film *Stop Making Sense*,[1] Byrne swings the suit around himself with increasing intensity as he dances and sings the audience into an ecstatic frenzy.

Many years later I accompanied The Big Suit on a trip to Cleveland to install it in the Rock and Roll Hall of Fame. I was working with David as his Art Director for the first decade of our current millennium—collaborating on and producing visual art and design projects and whatever arose in his infinitely creative polymathic mind—and we were also good friends. People who first became aware of him as the man in The Big Suit and on the cover of *TIME* magazine often asked me what he was really like; indeed, they continue to ask. I can answer that David is kind, curious, brilliant, funny, focused, and very generous. He is somewhat shy and can also be a bit socially awkward at times—he avoids eye contact, sometimes skips saying goodbye—but I grew up among research mathematicians, and his speech patterns and mannerisms seemed unremarkable to me. He clearly cares deeply about people, and has created his own way of being; he is simply very Byrneian.

The *what's the person really like?* question is common when it comes to public figures of all sorts, but it carries a particular valence

and urgency when it comes to David. It is born of early music videos featuring a dancing and singing figure who was "all neurasthenic nettles pointing inwards [as] he jerked and queaked (cross between quack and squeak)," as music writer Lester Bangs described in 1979.[2] Many fans identified very powerfully with his way of being-in-the-world on stage—a combination of alienation and intense connection and catharsis—and they urgently wished to know how he *actually* lived in the world. Other critics, too, often creatively evoked pathology, as in Pauline Kael's description of the figure in The Big Suit: "Byrne has a withdrawn, disembodied, sci-fi quality, and though there's something unknowable and almost autistic about him, he makes autism fun."[3] Bangs again: "He just looked like some nut just holidayed from the ward with a fresh pocket of Thorazine, that's all. There was something gentle, shy, reflective and giving about his hideous old psychosocial gangrene that made it seem less obnoxiously ostentatious."[4] As he reflected and refracted a way of coping with the ills of the world for us, did he bear a particular diagnosis himself?

In the early 2000s, articles started to appear in the mainstream media about a new understanding of so-called autism spectrum disorders—what *WIRED* magazine termed "The Geek Syndrome."[5] David had evolved quite a bit throughout his adult life, becoming, by all accounts, more adapted to social norms, but we were both reading these pieces with great interest, finding that he did indeed seem to have many of the defining characteristics of Asperger syndrome as they were then described. I recall asking him how he felt about the revelation, and he replied emphatically that he was *relieved*—that it explained many aspects of his experience, such as the extent to which he had found social interactions challenging or nonintuitive, particularly in his younger years. He has never been formally diagnosed, and he does not use his self-diagnosis as a pretext to ignore social cues or the like, but it offers a particular lens to understand his qualities. It is a potential framework, too, for the working-through of the balance

between individual alienation and society's neuroses—the ways Talking Heads were, as Bangs described, "about the individual human unit's . . . response to cybernation, depersonalization, the effect of corporate consciousness on individual identity, all those great contemporary questions nobody can seem to come up with any real or workable answers for."[6] Indeed, David's lyrics have always explored the relationship between the individual and the world, and the various suits he must put on to enter it. And the question of a *specific* pathology speaks to the broader question of where to locate pathology—in ourselves, or in the anomie of contemporary life?

At the same time, any effort to reduce David's way of thinking and creating to a diagnosis is clearly preposterous. His is an unending curiosity, and the Asperger syndrome revelation is but one aspect of his own journey. In his beautiful 2008 song "Never Thought," he writes, "I never thought my thoughts would be alright."[7] I have always interpreted the song as an affirmation—one which resonates deeply with me—of finding one's place after not having expected to, necessarily. To me it is about navigating one's differences, and being able to sing, finally, with joy: "And what I am is what I want to be." That is something toward which many of us—neurodiverse or otherwise—continue to aspire. And this must be the place, surely, that one reaches not simply through a particular diagnosis but through *living*—through, in Faulkner's words, "burrow[ing] into the world's teeming solidarity like a moth into wool . . . swallowing the substance of its warp and woof."[8] For while a label may seem to answer certain enigmas, it raises many more about identity, pathology, and the very nature of knowledge, as I learned when I experienced my own revelation of a lifelong medical condition.

And so we may ask ourselves: How do we situate and frame a retrospective diagnosis of a long-standing condition; what does it add—or subtract—if anything, and what can the experience teach us? This is the animating question of this project.

Notes

1. Jonathan Demme, dir., *Stop Making Sense* (Woodland Hills, CA: Talking Heads in association with Arnold Stiefel Company, 1984).
2. Lester Bangs, "Lester Bangs August 1979," in *Talking Heads: Chronology Deluxe* (London: Eagle Rock Entertainment, 2011).
3. Pauline Kael, "The Current Cinema: Three Cheers," *The New Yorker* (December 26, 1984) 112.
4. Bangs, "August 1979."
5. Steve Silberman, "The Geek Syndrome," *WIRED* 9, no. 12 (Dec. 2001), 175–183.
6. Bangs, "August 1979."
7. David Byrne and Brian Eno, "Never Thought," *Everything That Happens Will Happen Today* (2008).
8. William Faulkner, *Intruder in the Dust* (New York: New American Library, 1956), 158.

CHAPTER 1

Diagnosis

Met•ag•no•sis, *n.* [/ˌmɛtəˈnɑʊsɪs/]. Etymology: from *μετα-* across, changed, different, after + *γιγνώσκειν* to learn to know, perceive.
1. The revelation of a long-standing undetected condition effecting a change in the terms of knowledge.
a. *Medicine.* Diagnosis of a previously unobserved pathology, such as becoming aware that one is colorblind. May also occur when the diagnostic classification has shifted, as with the emergent and changeable category of autism spectrum disorders.
b. *Identity* etc. Revelation of knowledge bearing upon selfhood, such as genetic testing indicating genealogy differing from one's prior awareness.

Metagnosis

I begin by diagnosing a phenomenon which I term *metagnosis*. In the medical sense metagnosis occurs when one becomes newly aware, in adulthood, of a lifelong "condition." In the broader sense it describes any retrospective revelation pertinent to one's identity. In contrast to diagnosis, metagnosis effects a change in the terms of knowledge, such as a shift in our understanding of disease or of identity itself. Hence *meta*, for change, and *gnosis*, for knowledge.

Medicine is rife with neologisms utilizing Latin and Greek roots, and so I coin the term to describe a phenomenon which has heretofore lacked a proper name. Our focus is primarily the medical context, wherein metagnosis can occur in one or both of the following ways:

The first is when a long-standing condition has remained undetected by the individual and undiagnosed by medical professionals. For example, some people only learn in adulthood that their perception of color differs from the norm in some significant detectable manner—that they have one of several variants of so-called color vision "deficiencies." Another example is a midlife diagnosis of long-standing bipolar disorder, prompting a realization that certain behavioral patterns may be affected by a specific medical condition. Had such conditions been recognized earlier, they would typically have warranted diagnosis and, where applicable, treatment and/or accommodation. This phenomenon is distinct from (though it shares many common themes with) the experience of having troubling symptoms that have remained undiagnosed, misdiagnosed, or have received conflicting diagnoses. With metagnosis, one is not cognizant that one might be considered to have a medicalized condition until it is brought into awareness.

The second manner in which metagnosis can occur is when the diagnostic boundaries themselves shift notably. For example, many individuals have realized that they may well have been identified in childhood as having attention-deficit/hyperactivity disorder (ADHD) or dyslexia had the diagnoses existed or had they been more widely recognized and treated at the time. Often the awareness arrives when one's own child is diagnosed. Another example is, of course, Asperger syndrome, which was included in the psychiatric *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) in 2000 and entered cultural discourse in the United States in the years following, confronting some adults (like Byrne) with the notion that a critical aspect of their personality may be considered pathological—and, later, when the diagnostic categories shifted yet again and Asperger syndrome was largely enveloped into autism spectrum disorder, some learned that they no longer met the criteria.

Though both of these (frequently overlapping) types of metagnosis are fairly common, the experience of learning of a long-standing undetected condition is not widely recognized. While we devote a good deal of attention to the impact of shifting disease categories such as ADHD and autism spectrum disorders on children and adolescents, the effects on adults remain largely unaddressed. Thus the phenomenon is autological—possessing the property it describes—as it is itself long-standing yet generally undetected and unexamined. However, as we will find, it is a crucial fulcrum which destabilizes the balance between biomedical knowledge and lived experience, offering us the opportunity to better understand and rebalance them.

Relevance

I will examine the relevance and implications of metagnosis across a range of contexts, from its pragmatic aspects to the philosophical questions it evinces, as well the connections between these perspectives.

Relevance for individuals who encounter metagnosis: I begin with my own experience of discovering a long-standing visual field "defect" and will explore others' metagnostic accounts as well. Such revelations may arrive as welcome relief—as when an autism diagnosis provides an explanation for social difficulties—or may provoke resistance at being pathologized, or both reactions simultaneously. In every case it offers a potentially new framing of identity and experience which can be challenging to navigate and communicate. For if nothing has been altered save the awareness of the "condition," then what is its significance? In this sense metagnosis differs from learning of a newly acquired illness or injury, as it lacks the cultural scripts we employ for such changes. Because of this very uncertainty, however, it offers a fresh vantage point to see how our understanding of illness and identity is forged, for the individual who experiences metagnosis must situate or repudiate the information, revealing the ideological, cultural, and epistemological

presuppositions at play. I offer tools to render the experience more explicable for those who experience it.

Relevance for clinicians: Metagnosis casts doubt on the capacity of medicine—both its diagnostic acumen, in the case of undetected conditions, and its constancy and reliability, in the case of mutable disease categories. Such doubt can provoke a certain degree of defensiveness on the part of those in healthcare who are disinterested in acknowledging the field's own blind spots. Yet becoming attuned to this experience can help clinicians to better collaborate with and care for those who are navigating its challenges. Moreover, it can prompt those in clinical practice to look anew at the ways the medical discipline itself frames knowledge and structures experience, and to widen healthcare's field of view to encompass diverse and dynamic perspectives.

Relevance for our understanding of knowledge itself: Once upon a time, a man attempted to rob a bank but did not disguise himself for the security cameras. Later, when he was apprehended, he was astonished, protesting, "but I wore the juice"—meaning that he had rubbed lemon juice on his face, which he believed made him invisible in video footage. In the analysis of social psychologists David Dunning and Justin Kruger, this would-be bank robber's very lack of intellectual acumen prevented him from realizing that he was not bright enough to succeed as a criminal. Thus we have the Dunning-Kruger effect describing instances wherein people's very "incompetence robs them of the metacognitive ability to realize it."[1] Sadly, the United States president at the time of this writing is an exemplar of the Dunning-Kruger effect, which, as Dunning explains, "may well be the key to the Trump voter—and perhaps even to the man himself."[2] Even conservative op-ed *The New York Times* columnist David Brooks describes Trump as the "all-time record-holder of the Dunning-Kruger effect."[3] And referring to Trump as well as the British politicians "so breezily confident they could handle the results of a Brexit referendum," Oliver Burkeman writes for the UK *Guardian* that "historians of the future may refer to ours as the Dunning-Kruger era."[4] Given its timeliness, it is a phenomenon of vital importance, worthy of our attention.

Indeed, our recognition of our ignorance is the very basis of knowledge—a foundational concept in the Western philosophical tradition. As Socrates explains in Plato's Apology: "Surely it is the most blameworthy ignorance to believe that one knows what one does not know . . . if I were to claim that I am wiser than anyone in anything, it would be in this."[5] Roughly two millennia later (if you will forgive me for making this pairing) former United States Secretary of Defense Donald Rumsfeld frequently highlights the importance of remaining aware of our own lack of knowledge. He cites the categories of the *known known*, the *known unknown*, and the *unknown unknown*—the arena in which we are ignorant of our very ignorance, and do not even know to ask the proper questions.[6] However, as philosopher Slavoj Žižek points out, there is yet another category: "What [Rumsfeld] forgot to add was the crucial fourth term: the *unknown knowns*, the things we don't know that we know . . . the disavowed beliefs, suppositions and obscene practices we pretend not to know about, even though they form the background of our public values."[7] Thus the *unknown known* term is itself an *unknown known*—autological, just like metagnosis. And, surely, we are so often content to *not* bring the ideological framework (or the fantastical id) subtending public discourse into our conscious awareness.

In this context, metagnosis precipitously reveals an *unknown unknown*, moving it into knowledge—*I didn't realize I had ADHD, and now I do.* But the recognition also illuminates our forms of knowledge, exposing the *unknown knowns*—the ways that categories of normalcy and difference, or the diagnostic boundaries of a condition such as ADHD—are contingent, ideological, porous, labile, though we often prefer not to view them as such. Moreover, it raises questions about the relationship between narrative and knowledge, and the ways in which we construct our self-conceptions in relation to such diagnostic categories. It demonstrates ineluctably that the field of identity is what Lennard Davis terms "the biocultural," situated at "the intersection among the cultural, social, political, technological, medical, and biological"[8]—a complex and dynamic terrain.

The relevance and implications of these questions extend well beyond any given instance of metagnosis, for the phenomenon sheds light on the spectrum of human experience. As sociologist Erving Goffman explains, "realms of being other than the ordinary provide natural experiments in which a property of ordinary activity is displayed or contrasted in a clarified and clarifying way. . . . *seeing these differences (and similarities) means seeing.* What is implicit and concealed can thus be unpacked, unraveled, revealed."[9] When it comes to medical diagnosis, "ordinary" pathology generally implies that which *can* be identified and categorized; yet it is here, in the apparently *extra*ordinary realm, that metagnosis emerges as a concept relevant to the entire gamut of seemingly ordinary experience, troubling the distinction between ordinary and extraordinary. For when qualities of one's character are suddenly associated with, say, a diagnosis of being on the autism spectrum, it calls into question the degree to which one's self is determined by biological and environmental factors—a dramatic and perhaps upsetting rift in day-to-day experience. Yet we will all face these questions soon enough; indeed, we are already. As our medico-scientific knowledge continues to accelerate exponentially, we will continue to learn, increasingly, that more and more aspects of our identities can be understood in biomedical terms and plotted on new spectra as yet unimagined. How might metagnosis illuminate these trends—trends that worldview holism characterizes as moving us toward "a reductionistic biopathological understanding of the body"? How does it help to paint a portrait of "an anomic modernity, which produces and constitutes its own sort of spiritual sickness"?[10] How can it guide us in negotiating individual experience, medical categories, and social determinants in the face of such revelations? Finally, what are the implications for our understanding of identity itself?

Metagnosis offers a particular lens to better understand these issues by looking to the limit case for insight into all cases. This investigation is hence moving from the personal to the broadly conceptual and back again, as well as from the medical to the philosophical and political—and, again, back again. In the process I am concerned, always, with what remains unseen—my own scotomas

(literally and figuratively)—the limitations and blind spots of this endeavor.

Plan

We begin with diagnosis and treatment of this newly named (yet not so new after all) condition of metagnosis. As I will describe in Chapter 2, the methodology is an elaboration of narrative medicine, comprising the pillars of interdisciplinarity, narrative attentiveness, and the creation of a writerly text.

In Part II I tell the tale of my own vision. Beginning with strabismus, or crossed eyes, and "lacking" stereo-vision, I put my own story into conversation with such figures as neurologist Oliver Sacks, neurobiologist Sue Barry, and nineteenth-century English schoolmaster Edwin Abbott Abbott to explore themes of communicability, alterity, and narrative ethics. Is it possible to see in different dimensions? What are the implications of telling a particular story of seeing? I then recount my own metagnostic revelation, that of a long-standing visual field "defect," and address its particular narrative challenges. Next, I describe yet another revelation concerning my vision—that of *blindsight*, or unconscious vision. I propose that the figure of blindsight is a useful model for addressing this quite paradoxical phenomenon of metagnosis.

In view of the narrative difficulties posed by metagnosis, Part III elaborates the phenomenon's own narrative arc comprising three stages: recognition, subversion, and renegotiation. First, a metagnostic revelation often provokes an experience of *recognition*, as it appears to explain prior difficulties. Beginning with the model of passing, we will trace experiences and forms of recognition through real-world and fictional examples, from *Oedipus* to *Blade Runner*. Drawing upon recognition's conceptualization—from Aristotle to twentieth-century science fiction editors to literary theory and criticism—we find a form of *mis*recognition which characterizes, too, the experience of metagnosis, as labels may be simultaneously reductive and liberating. Following recognition is

the stage of *subversion*, as metagnosis unsettles many of our categories and definitions, from disability to disease itself, as well as our customary means of representing these states. Finally, some metagnostic experiences result in a *renegotiation* of the terms which have been unsettled, requiring a form of blindsight to apprehend them in new ways. Making analogies to a range of contexts such as historical diagnosis and translation, we will explore the possibilities for forging fresh understandings. These stages are not comprehensive nor prescriptive, yet they offer a framework to better understand metagnosis.

In Part IV we will explore a range of metagnostic stories, drawing upon oral history interviews and memoir. How do these narratives reflect the arc of recognition, subversion, and renegotiation? How might we deploy the figure of blindsight in contemplating the issues they raise? Metagnosis, I argue, is the key to making a readerly/writerly diagnosis. As literary movements such as metafiction expose the fallacies and limitations of literary realism, metagnosis constructively exposes the representational practices of medicine. Moreover, the implications extend beyond the context of health and medicine to revelations concerning identity and to the cultural discourse of identity writ large.

Understanding metagnosis—as a revelation effecting a change in knowledge—is integral to our understanding of ourselves and of identity itself as we move into an increasingly dynamic future.

Notes

1. Justin Kruger and David Dunning, "Unskilled and Unaware of It: How Difficulties of Recognizing One's Own Incompetence Lead to Inflated Self-Assessments," *Journal of Personality and Social Psychology* 77, no. 6 (1999), 1121. See also Errol Morris, "The Anosognosic's Dilemma: Something's Wrong but You'll Never Know What It Is (Part 1)," June 20, 2010, opinionator.blogs.nytimes.com/2010/06/20/the-anosognosics-dilemma-1.
2. David Dunning, "The Psychological Quirk That Explains Why You Love Donald Trump," May 25, 2016, www.politico.com/magazine/story/2016/05/donald-trump-supporters-dunning-kruger-effect-213904.

3. David Brooks, "When a Child Is Leading the World," *The New York Times*, May 15, 2017, A27.
4. Oliver Burkeman, "There's a Big Difference Between Those Who Realise They're Winging It, and Those Who Don't," *The Guardian [UK]*, October 28, 2016, www.theguardian.com/lifeandstyle/2016/oct/28/big-difference-those-realise-winging-it-those-who-dont.
5. Plato, "Apology," in *Plato, Complete Works*, trans. C. M. A. Grube, ed. John M. Cooper and D. S. Hutchinson (Indianapolis, IN: Hackett, 1997), loc. 29b.
6. Donald Rumsfeld, *Known and Unknown: A Memoir* (New York: Sentinel, 2011), 13–15.
7. Slavoj Žižek, "What Rumsfeld Doesn't Know That He Knows about Abu Ghraib," May 21, 2004, www.lacan.com/zizekrumsfeld.htm. Relatedly, Christopher Bollas termed "that which is known but not yet thought" the *unthought known*, exploring the potential for its emergence in psychoanalysis. Christopher Bollas, *The Shadow of the Object: Psychoanalysis of the Unthought Known*, 30th anniversary ed. (London: Routledge, 2018), xv.
8. Lennard J. Davis, *The End of Normal: Identity in a Biocultural Era* (Ann Arbor: University of Michigan Press, 2014), vii.
9. Erving Goffman, *Frame Analysis: An Essay on the Organization of Experience* (Boston: Northeastern University Press, 1986), 564 (emphasis added).
10. Charles E. Rosenberg, "Holism in Twentieth-Century Medicine," in *Greater Than the Parts: Holism in Biomedicine, 1920–1950*, ed. Christopher Lawrence and George Weisz (New York: Oxford University Press, 1998), 341–42.

"In this important and compelling volume, Danielle Spencer charts complex questions of self and identity, of normality and exceptionalism, exploring with elegance and skill the links between theory and personal experience. Her work is brave, lucid, and insightful."

—Andrew Solomon, author of *Far from the Tree: Parents, Children and the Search for Identity*

"*Metagnosis* is masterful, original, filled with electric thinking, sparking, glinting, illuminating corners so dark we didn't know they were there. In today's storytelling fever, all who tell and listen to stories need deeply perceptive guides who provide conceptual and practical frameworks for interpreting narratives' complexities. Danielle Spencer has emerged as a rare intellectual quester and pioneer who provides theoretical and methodological clarity to narrative medicine and all such efforts to comprehend the lives lived around illness, health, and care."

—Rita Charon, author of *Narrative Medicine: Honoring the Stories of Illness*

"Unlike any other book I've read, *Metagnosis* is hard to describe but easy to praise. Radiant with originality, deeply researched, ever absorbing, this thrillingly ambitious hybrid of medical, cultural, and personal history is also a work of passionate imagination."

—Sigrid Nunez, author of *The Friend*

"*Metagnosis* is a brilliant, nuanced, and exciting exploration of the multiple ways people come to understand a medical 'condition.' Moving deftly from one discipline to another as she examines their various epistemologies, Spencer pries open her own story and the stories of others. She interrogates the grand cultural narratives and reductionist models that have shaped medicine and exposes their limits, their meanings, and their politics. This is a book that blasts apart conventional categories and pushes its reader to think again. I loved it."

—Siri Hustvedt, author of *The Blazing World*

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