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*Metagnosis: Revelatory Narratives of Health and Identity* by  
Danielle Spencer (review)

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# Book Reviews

**Danielle Spencer, *Metagnosis: Revelatory Narratives of Health and Identity*.** New York: Oxford University Press, 2021. xv + 369 pp. Hardcover, \$39.95.

Danielle Spencer's *Metagnosis: Revelatory Narratives of Health and Identity* is a landmark and deeply imaginative contribution to work at the interfaces of biomedicine, psychiatry, humanities, literature, popular culture, cultural studies, disability studies, memoir, and personal narrative. It fills an important niche in the interdisciplinary domains of health humanities, medical humanities, and narrative medicine and is a welcome contribution to these fields. Indeed, I think we can see it as a "next generation" diffraction of those fields as they move from exploring interdisciplinary connections toward making confident discoveries and assertions of their own. Spencer writes much of the book in the first person as she explores her own experiences with extraordinary vision, medical diagnostic categories, surgical procedures, critical theory, and narrative medicine. She brings extensive scholarship to the process informed by her role as academic director of the Columbia University narrative medicine master's program and as co-author of *The Principles and Practice of Narrative Medicine*. *Metagnosis* is thus not only a lively and enjoyable read; it is an education and masterclass in the uses of literature and humanities for understanding and navigating health, health care, and embodied identity more broadly.

At its heart, *Metagnosis* is a form of "autotheory" that deftly weaves together personal narrative of embodied experience with analysis and criticism of experience and the multiple discourses and institutions that surround and shape such embodied and enculturated experiences (35). This means there is no science/humanities divide in the text; the two have become so deeply cross-connected and intertwined that they work together like obvious collaborators—think of Uhura, Spock, and Bones—even when they are also at times antagonists and in conflict with each other. This welcome biocultural complexity effortlessly troubles and holds in tension binaries between medical/health humanities (focusing on the individual and the clinical encounter) and critical medical humanities (focusing on the social/political/cultural power dynamics

that surround that encounter). By weaving both the personal and the critical together, we can see how critical humanities can be part of an affirmative skill set (a “treatment” method, as Spencer puts it) useful for both individuals and biosocial/biopolitical communities who are navigating the world of bodily and mental difference and the many paradoxes, dilemmas, and conflicts that inhabit that world.

Part 1 of the book begins with Spencer’s coinage of a new term, *metagnosis*.

**Met•ag•no•sis**, *n.* [/,metəˈnəʊsɪs/]. Etymology: from *μετα*-across, changed, different, after + *γινώσκειν* to learn to know, perceive.

1. The revelation of a longstanding 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. (3)

Spencer argues that *metagnosis*, as a phenomenon, is becoming increasingly common as biomedical and genomic knowledge continues to develop. With increasing diagnostic categories and screenings (not to mention global pandemics and global medical surveillance and intervention), *metagnosis* serves as a bellwether for how we *all* must navigate biomedical and genomic research that is rapidly bleeding out of the laboratories and the clinics and moving further and further inside everyday lived experience and cultural formations. This means, for Spencer, we all need new and evolving languages to navigate emerging biomedical formations. And, it means, at least for me, that scientific researchers and their journalistic and marketing promoters are not the only ones who can, *or should*, be empowered to make meaning and coin terms. All of us, or as Spencer puts it, all “fellow persons with bodies,” can and must be included in new languages and narrative creations for new times (299). Spencer’s complexity certainly shows the way for collaborative work at the interface of science and humanities. But it also makes clear that those of us engaged in this work cannot wait for an invitation to be included in biomedical narratives and linguistic developments; we must use direct action as needed.

Part 1 also explores the methodology of the book and proposes powerful tools for understanding and navigating experiences of met-

agnosis. Spencer's methodology section deserves particular comment, as she articulates a novel line of research that she calls a "narrative medicine approach" to her topics (15). "Narrative medicine," in its initial formulations, has been an applied method for teaching an aspect of clinical competence—called specifically "narrative competence"—in order to enhance clinical skills of recognizing and empathically understanding the stories of illness. Deeply respecting narrative medicine as a teaching tool, Spencer takes it a step further. In Spencer's hands, narrative medicine also becomes a method of original research, designed to open new paths to knowledge and deeper understanding of complex topics at the interface of biomedicine, lived experience, and cultural context.

Spencer carefully articulates three key moments in a narrative medicine approach: *interdisciplinarity*, *narrative attentiveness*, and *construction of writerly texts* (15). Interdisciplinarity is essential, since biomedical topics are never contained by biology alone but are complex amalgams of biological, experiential, psychological, social, cultural, creative, spiritual, and political domains. Narrative attentiveness grounds deep interdisciplinary study in the narrative arcs of lived experience. This is critical because, although a narrative medicine methodology is open to multiple disciplinary domains, it also stays close to the way this openness is processed and organized in lived stories, personal choices, and cultural practices of navigating biological diversities. The ground of this method, the criterion by which distinctions and judgments are made, is therefore not universal science or ethics (grand narrative conceptions of the true or the good), but much more local and diverse narrative consequences and possibilities. As such, key grounding questions in a narrative medicine approach include: what does it mean for the lived experience and life practices of a person, a family, or a community to make particular meanings and tell particular embodied stories of the past, present, and possible futures? Who is empowered to decide? What tradeoffs will they choose?

And, finally, narrative medicine methodology lends itself particularly well to "writerly texts," which Spencer describes as a style that moves beyond genre norms and expectations to allow a blending and unsettling of genres. This allows the creation of an autotheoretical self-exploration in which Spencer appears as a character and at the same time draws on deep interdisciplinary scholarship:

Ultimately, that is the goal of this project—to conduct a sustained and nuanced effort to put the discourse of biomedicine in perspective with others in order to better understand how they are constituted,

and how we may develop robust new ways of seeing. Moreover, a complex writerly text allows for the narrative development of the investigation; rather than presenting a full and final picture at the outset, it permits us to explore the in-between, the realm between sickness and health, between illness and identity, and the liminal space between other seemingly categorical distinctions. In conducting the project in this manner I respond to . . . call[s] for “a new transdisciplinary vision of lived experience creating a nexus between the humanities and the life sciences.” (46)

Despite her clear emphasis on writerly complexity, Spencer is also imminently attentive to her interdisciplinary audience, and she creates a text that is at the same time exploratory and immensely readable. Her attention to lived experience—what does this complexity mean for how we should live?—grounds both the exploration and a writing process that cares about reader responses. This is not cynical destruction of categories and disciplines; it is earnest and sincere exploration of where are we now, how we got here, and how we might proceed as individuals and as collectives.

After these methodological innovations, Spencer uses Part 2 to recount and explore her own experience of metagnosis in the realm of vision. The first chapter in this section, “Flatsight,” articulates Spencer’s experience with childhood strabismus (misaligned eyes), the shame and stigma of growing up cross-eyed, the multiple surgical treatments designed to intervene, and the eventual realization that her vision “lacks” binocular capacity. I put the term “lacks” in quotation marks because Spencer nicely compares different memoirs in this domain, which she calls “stereo-narratives,” to consider how value judgments depend on how much the person adopts ableist binaries and hierarchies of normal and pathological in this domain (65).

The next chapter, “Half-sight,” articulates where her metagnosis first occurs—with the realization that she has had a longstanding visual field “defect” on the right side and the resultant difficulties narrating and communicating this realization. And in the chapter “Blindsight,” Spencer beautifully articulates her discovery of a kind of unconscious vision of movement that has the effect of undoing ableist binaries of visual field “defect” and “pathology” through which she was originally diagnosed.

Part 3 brings attention to a common “narrative structure” or “narrative arc” of metagnosis in three separate chapters: “Recognition,” “Subversion,” and “Renegotiation.” Spencer makes it clear

“this schema is neither comprehensive nor prescriptive,” rather it is a framework to work with, to use if it is helpful, and to discard if it is not (163). During the course of these chapters, Spencer makes the compelling case that both “metagnosis” and “blindsight” offer potent real-world experiences that spontaneously (if handled in a narrative medicine methodology) destabilize binary distinctions and undermine the often rigid hierarchies that follow from either of these alone. This powerful argument and demonstration shows how deconstruction (and reconstruction) is not something that happens only in philosophy and literary theory but is something that happens in the world—with the world of biomedicine being a particularly fertile field for these kinds of recognitions, subversions, and renegotiations. Perhaps most important, metagnosis and blindsight not only demonstrate worldly deconstruction, they open up to an array of third-space alternatives for navigating and negotiating difference beyond binary sedimentations.

These subverting and renegotiating third spaces inhabit metamodernist terrains that toggle between modernist truth and postmodernist contingency. Both modernist truth and postmodernist contingency tend to erase our agency and our pragmatic choices. Certainly our agency is limited as we recognize and misrecognize ourselves in the linguistic systems that hail us. But, at the same time, we do have the possibility of subverting the cultural narratives that shape us and of negotiating and navigating the often complicated consequences of the linguistic callings—which too often are contradictory combinations of stigmatizing and empowering, pathologizing and politicizing, all at the same time. Third-space writerly methods and interdisciplinary communities allow for pragmatic and consequentialist exploration of the pluri-dimensional possibilities of different ways of making meaning and telling stories. Negotiating these possibilities is not a luxury; it is an inescapable part of our contemporary experience. Our agency may be limited by a world of deterministic events and structured meanings, but that does not destroy our agency. It only highlights the need to pay attention to and foreground the narrative freedoms and choices we do retain.

Part 4 nicely comes out of autotheory to consider a range of related experiences drawn from oral history and memoir. Spencer’s use of memoir is as effective as her use of autotheory. She shows how invaluable memoir can be as a space of research and knowledge creation in the domain of embodied differences. This section opens to a wealth of additional research examples approachable through a narrative medicine methodology, including autism, ADHD, face-blindness, and synesthesia. If I wanted more from the book, it would be here.

Spencer's readings of these topics through combining memoir and theory is so fresh and illuminating that one cannot but wish she had more time to explore these topics and beyond. Clearly, work for future projects.

And, finally, Spencer's last chapter brings the reader home to a deep realization of the need for ongoing interdisciplinary writerly research, not only in the world of health and health care, but also in larger-world questions of identity and identity politics. Spencer explores the confluence of metagnosis with works of metafiction that highlight the limitations of literary realism. In addition, she uses examples of metareferential memoir, genomic identity revelations, and musician David Byrne and comedian Hannah Gadsby's experiences with the category "autism" to think through the implications for identity and identity politics. Metareferential practices, writ large, provide tools for navigating the value of identity, its role in giving shape to our self-understanding, and its uses in the struggles against institutional prejudice and stereotypical essentialisms, while at the same time being alive to what Spencer calls "identity's complexity, internal contradiction, and intersectionality" (318). In short, Spencer's narrative medicine methods have value in working through a range of identity concerns and struggles without clogging our categories along the way.

Spencer's *Metagnosis: Revelatory Narratives of Health and Identity* is a major contribution to the literature. It develops and performs a new flowering of the fields of narrative medicine and health humanities by working out a methodology for creating new knowledge at the interface between biomedicine and wider human knowledge. The figures explored and the writerly methodology developed are highly relevant to multiple health-related experiences and will only continue to be so in the future. Affirming and creating third spaces for understanding and negotiating these experiences are essential life enhancements and cultural practices as biomedicine continues to evolve. Spencer's work is a model for future research in these domains. It is done with masterful skill and extensive interdisciplinary research. It's a gift to all of us, the fellowship of persons with bodies, who must navigate and negotiate the too often conflicted terrain of bodily difference and impermanence.

Bradley Lewis