



# Metagnosis: Revelatory Narratives of Health and Identity by Danielle Spencer

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Arthur W. Frank<sup>1</sup>

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Danielle Spencer coins the word *metagnosis* to describe something recent as it refers to medical diagnosis but old in its broader implications. “In a medical sense,” Spencer writes, “metagnosis occurs when one becomes newly aware, in adulthood, of a lifelong ‘condition’” (3). Spencer herself experienced metagnosis when she was diagnosed as having a visual field limitation. As a child she had eye problems, but she had not realized that her vision was restricted or that was a diagnosable “condition.” Her book is, in part, an illness narrative of that discovery. But metagnosis expands to describe “any retrospective revelation pertinent to one’s identity” (3). Thus Spencer, like Erving Goffman in his classic analysis of stigma, moves from some people’s particular problem to everyone’s issue.

I happened to finish *Metagnosis* on the day that my rereading of Charles Dickens’s (1998 [1853]) *Bleak House* reached the pivotal Chapter XXXVI, when Esther Summerson, who had always known herself to be an orphan, finds out who her mother is. “For my agitation and distress throughout were so great that I scarcely understood myself,” Esther tells us; “I had had experience, in the shock of that very day, that I could, even thus soon, find comforting reconcilements to the change that had fallen on me” (620, 625). *I scarcely understood myself*—that’s the effect of metagnosis. Esther’s response to this revelation is, first, scarcely understanding who she is in light of what is learned; her sense of reconciling herself to her new knowledge will continue to be tested. Metagnosis recognizes the inseparability of the knowledge itself and the process of change that this knowledge effects.

*Metagnosis* arrives as health humanities is defining itself as a field. Textbooks are starting to appear, which is a sure sign that what was a shared commitment of individual scholars and health professionals to some combination of teaching, research, and clinical practice is becoming a bureaucratically defined entity within the political economy of universities, granting councils, and publishers. As an intervention in this field, *Metagnosis* has an intellectual sophistication that gives health humanities increased credibility by commanding a broad readership. Spencer moves beyond programmatic writing proclaiming the need for health humanities; she demonstrates what can be done in this new field. Her full length, intricately integrated book shows specifically medical issues as one aspect of how

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✉ Arthur W. Frank  
arthurwfrank@gmail.com

<sup>1</sup> University of Calgary, Calgary, AB, Canada

society is based on a distribution of knowledges that, by categorizing identities, affect who people think they are and who they believe they can be.

The book's interdisciplinary breadth deserves a review symposium. Philosophers of science, analysts of clinical logic and practice, disability studies scholars, and theorists of identity will foreground different aspects of Spencer's writing. Her ability to play those differences against each other makes the book a constantly turning prism, refracting shifting shadings of light. Spencer's distinctive style follows the conventions of scholarship, even as it reconfigures these conventions.

Spencer teaches in the Program in Narrative Medicine at Columbia University, and she situates her book as a work of narrative medicine, which she describes as a "research methodology involving three pillars" (15). "Methodology" here is not a prescribed method: these pillars are intersecting commitments that set parameters for the innovation of project-specific methods. The first is to interdisciplinary, and no one draws upon such diverse literatures, from neuroscience to literary studies, with a greater level of detail, precision, and clarity. The second commitment is to what Spencer calls "narrative attentiveness," which in my paraphrase means attention to what different forms of texts do and are useful for doing. Narrative attentiveness recognizes that knowledge is enacted—it happens—in textual forms, and those forms are always artful in how they shape the knowledge they present, anticipating its effects. Third is the commitment to "constructing a *writerly text*" (15, original emphasis). What that means is better exemplified by *Metagnosis* itself, as a text, than any definition can explain. Spencer makes herself a "visible presence" (35) in her writing; the question of epistemic authority is always self-conscious, whether that is medical authority or Spencer's own claims. She offers several examples of writerly texts, summarizing them as bridging "memoir, criticism, and other generic boundaries, challenging the reader to engage in a dynamic meaning-making process" (35). *Metagnosis* engages readers in that process, keeping the dialogue open. Rarely does so much scholarly expertise find such a compelling first-person voice, speaking so directly to the reader.

Parts of *Metagnosis* are technical, especially the autobiographical sections. It's beyond the scope of this review, and beyond me, to summarize the complexities of diagnosing Spencer's visual field disorder. One crucial moment is when she discovers she has what is called *blindsight*, which is what the word implies: some people's capacity to respond to what happens in the "blind" sections of their visual field. Blindsight is being able to respond to—and thus in some sense to see—what is not consciously seen. Thus, blindsight stretches what we mean by *perception*, as well as the limits of what we call cognition. Spencer makes blindsight a metaphor for metagnosis itself: it undoes the binary division between what is known and not known, seen or not seen.

Spencer presents metagnosis as a narrative process with three segments: recognition, which is learning that what was vaguely sensed about oneself has a name and classificatory category; then subversion, in which the instability of that category is realized, as it fits but fails to encapsulate the lived reality; and finally renegotiation, in which someone figures how to live with the category, including positioning oneself between "I have" and "I am."

Within that narrative arc, I foreground three issues that Spencer builds, each upon the others. One is the relationship between medical diagnosis and the sense of self. Physicians do not generally think of their work as performative; they understand themselves as messengers, only reporting what is already, objectively there. Spencer contributes to a corpus of research that shows how the pronouncement of a diagnosis enacts a new form of identity for the person as patient. More exactly and in my paraphrase, a diagnosis is a not yet renegotiated bid to form an identity. Second, that issue leads to a discussion of categories, including but extending beyond diagnostic categories: their power, instability, and

subversion. The big issue here is the “epistemic renegotiation of [medical] positivism and [social] constructionism” (239), that constructionism most clearly exemplified in the social model of disability. Third, these discussions entitle Spencer to assert how medical recognition in diagnosis, like *any* recognition of identity, “is also a misrecognition” (276).

This claim seems the reverse of blindsight: we actually know less than what we are quite sure we can see. How, if we take that seriously, do health professionals do their work, and the rest of us live our lives? The recognition of metagnosis, as indicative of how much of medicine specifically and cultural categorization generally work on people, is a call for a new form of life, both in how we hold individual identity and how we relate to others in their identities. In the end, Spencer proposes that “all diagnosis can and should be metagnosis” (307). That assertion is as radical as it is well earned by the weight of scholarship and personal testimony, including interviews, that lead Spencer to it—including the book’s effective deconstruction of any binary relation of epistemic privilege between what counts as “scholarship” and personal testimony.

Reading *Metagnosis* would have prepared Esther Summerson to deal with the recognition that is forced upon her by becoming a self-consciously critical renegotiator of identity. The book would have showed her how her problem was hardly hers alone. Nor was it much of a coincidence that I read Esther’s story on the day I finished Spencer’s book. Metagnosis stories are all around and always have been. We can see them more clearly and grasp the extent of their implications, now that Spencer has given us a word that names them.

Medical science is proliferating crises like Esther Summerson’s, most widely through the knowledge claimed and distributed by genetic testing, telling people who they always have been but had not known themselves to be. As the cutting-edge technologies of knowledge/identity production intensify an old dilemma, they make it possible to call that dilemma for what it is, to negotiate and subvert it. What is new is Spencer’s book: its weaving of multiple knowledges, its attention to narrative forms and their effects, and its demonstration of how to be writerly as the honest recognition that the writer’s relation to readers is a relation between persons, enabled and limited by their language.

Danielle Spencer has the gift of seeing that there is always more: another layer of meaning, another instability of claim or category, another connection in which two elucidate something about each other. When colleagues outside health humanities ask what the field can accomplish, this book is now my answer.

## References

Dickens, C. 1998 [1853]. *Bleak House*. New York: Book-of-the-Month Club.

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