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Sayantani DasGupta and Marsha Hurst (eds.), *Stories of Illness and Healing: Women Write Their Bodies*, Kent State University Press, 2007

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Stories of Illness and Healing: Women Write Their Bodies is the latest collection in the 'Literature and Medicine' series from Kent State University Press. This series, which began in the early 1990s, publishes texts that are conceived of, at least partly, to be used in the medical humanities and narrative medicine programs that are increasingly a component (sometimes required, sometimes optional) of medical school curricula, especially in the United States. The editors, Sayantani DasGupta and Marsha Hurst, are both active in such programs in the New York City area. DasGupta, an MD/MPH, is faculty in the Division of Pediatrics and the Program in Narrative Medicine at Columbia University, and Hurst, whose training is in Political Science, has played a leading role in the formulation and institutionalization of the emergent interdisciplinary field of health advocacy. She currently teaches in the Narrative Medicine program at Columbia.

The editors explain that the anthology emerged out of their teaching and advocacy work in New York, and their 'desire to find such a collection that we could use in our classroom teaching' (p. xii). Their text incorporates a vast range of writing by women (and one man) about the experiences of illness and healing. By juxtaposing poetry, memoir, fiction, ethnography, monologue, and scholarly essays, the text as a whole demonstrates the struggle to find a form adequate for telling stories of suffering. This struggle with form also animates many of the individual pieces, or animates *and haunts* them, in the case of one of the anthology's most moving pieces, Laura Rothenberg's 'My so-called lungs'. Rothenberg's piece about living with cystic fibrosis as a 21-year-old college student was produced for Radio Diaries and aired on National Public Radio in 2002. The transcript of Rothenberg's radio diary is reproduced here, and, although the printed text can't capture the exact timber of Rothenberg's voice, marked as it is by the effects of cystic fibrosis, we do get a sense of how this particular form works well to capture Rothenberg's experience of living with, and eventually dying from, cystic fibrosis. We hear her facing chronic illness with irreverent humor in the midst of family and friends, at the hospital and at university, where she has a 'lung retirement party' before her lung transplant. We also hear the loneliness of chronic illness, as she describes the many complications following her transplant, and admits at the end of the transcript that she doesn't really 'count on anything anymore. I just go with the flow. I think that's okay' (p. 44).

Stories of Illness and Healing makes the argument that reading stories like Rothenberg's allows for a much denser presentation of the experience of illness than

medical students and other health practitioners are likely to get on grand rounds. The point isn't that reading and writing stories like those anthologized here should replace grand rounds, but that such stories can give voice to what is so often excluded from clinical narratives of disease: suffering and empathy. After two introductory pieces by DasGupta and Hurst on 'The gendered nature of illness' and 'The history of women's illness narratives', the anthology is organized into sections on narratives of body and self, diagnosis and treatment, womanhood, family life and caregiving, professional life and illness, and advocacy. Each section is introduced briefly by the editors and is followed, usually, by a longer essay that seems intended to provide a particular discursive frame (literary, historical, sociological, policy) to the section's theme.

While the editors acknowledge that the majority of the authors in the collection are from the United States and Canada, they also introduce the contributors as 'a group of women diverse in age, ethnicity, education, socioeconomic background, sexual orientation, nationality, profession, and writing experience' (p. xi). But, as I read the various pieces and checked on the brief author biographies at the back of the book, I was struck by how many of the contributors are from New York. That this should be the case is not really surprising, or necessarily bad. I do think, however, that situating the text in relation to a particular place and some of its institutions might have led the editors to a different way of framing their topic, from an investigation into *women's experience* to an investigation into particular ways of doing illness, doctoring, and advocacy. Admittedly, this is a language I myself prefer, and try to use in my own work. Why? Because I think it is important to put into question, and not take as self-evident, both the category 'women' and the category 'experience'.

In their introductory essay on 'The history of women's illness narratives', Hurst and DasGupta discuss Kathlyn Conway's memoir *Ordinary Life* (1997) as a 'narrative about connections' (p. 13), and note that Conway's voice is both angry and relational (p. 14). They quote a passage from Conway's memoir that describes her thoughts as she waits in the office of the breast surgeon before her biopsy:

On his wall is a painting of a man who I imagine is his father, perhaps the other doctor named Cody whom we found in the phone book. I'm glad he has a father. Does he have children? I want him to know that what matters most about possibly having breast cancer is that I am part of a family. I have parents, a husband, and children. (p. 14)

Hurst and DasGupta read this passage as demonstrating that 'Conway's illness is inseparable from her caring relationships'; and they add, 'for Conway, empathy on the part of the health professional would require familial consciousness' (p. 14). But I read the same passage as demonstrating a preoccupation with normalization. On the one hand, this makes sense: people who are ill want to get better, want to feel 'normal' again. We see this desire in many of the contributions, and this explains why some of the effects of cancer treatments, like hair loss, are often more disturbing to some women than the cancer itself: women without hair look strange to others and themselves, more so, perhaps, than men do. On the other hand, the 'familial consciousness' required for empathy seems to also require a rather normative concept of the family. My question is again about categories: what is this category 'familial consciousness'? What I'm interested in, and what I think the experiences and events of illness help us to begin to investigate, is what Bourdieu

(1998: 67), in a short essay on 'The family spirit', calls 'the specific ontology of social categories'. 'Everytime we use a classificatory concept like "family"', Bourdieu (1998: 66) argues, 'we are making both a description and a prescription, which is not perceived as such because it is (more or less) universally accepted and goes without saying'. It is the prescription behind or below the description of 'women's experience of illness' that concerns me in reading many of the contributions here.

In their introduction, Hurst and DasGupta extend Conway's personalized analysis of caring by contrasting it with Carol Levine's essay 'Night shift', which opens the first of two sections on advocacy. This move in their introduction mirrors the overall structure of the book, which shifts from personal narratives to narratives that are attentive to structural violence. I like the book's trajectory, because some of the later texts, like Levine's, disrupt the tendency toward normalization in some of the earlier pieces. Levine, for one, doesn't valorize women's traditional caregiving roles; rather, she examines the often pernicious effects of such traditional roles. Levine directs the Families and Health Care Project in New York City and is the former editor of the *Hastings Center Report* and managing editor of *IRB: A Review of Human Subjects Research*, and she also became her husband's caregiver after he became 'totally disabled, essentially quadriplegic' following an automobile accident (p. 241). Levine takes on 'the system', which, she argues, benefits from the assumption that women are 'hard-wired for wound dressing, feeding tube calibration, and wheelchair manipulation' (p. 242). As Bourdieu (1998: 67) says, 'nothing seems more natural than the family; this arbitrary social construct seems to belong on the side of nature, the natural and the universal'. If it is 'natural' that women should care for others in the context of the family, then the system – the State – is left off the hook and doesn't have to create non-familial or other-familial structures of care. Levine's critique of the system and the heroic narratives of women caregivers that support the system emerges out of her 'professional experience working with AIDS advocates, mostly gay men', an experience which she proudly admits has 'skewed [her] sense of reality' (p. 242). In the gay and lesbian community's response to AIDS in the USA, the categories 'family' and 'caregiver' – not to mention 'man' and 'woman' – get queered. What I think is important about this essay is that it challenges a certain knowing familiarity, a limited and limiting it-goes-without-saying understanding, of women's experience.

Why should doctors, nurses, and other health-care providers read and write illness narratives? Rita Charon's essay 'Narrative house calls and cultural memory', which closes *Stories of Illness and Healing*, offers an answer to this question. Or, perhaps it doesn't so much offer an answer as a method. Narrative medicine seeks to make use of the four components Toni Morrison describes as necessary for the 'practice of great art': memory; perception; imagination; and knowledge (p. 311). Charon, who is director of the Program in Narrative Medicine at Columbia, extends Morrison's method to clinical practice, her own, and, through her teaching in narrative medicine, beyond her to others. I think Charon's essay offers a fitting end to this book because it encourages the reader to think about why the narratives they have just read matter, not just in the sense of why they are important, but in terms of what they materialize for us.

References

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