

BOOK REVIEW

Distributed Narrations of Illness

Patrick Anderson. *Autobiography of a Disease*. New York: Routledge, 2017. Paperback ISBN 978-1-138-74450-9. Hardcover ISBN 978-1138744486. Ebook ISBN 978-1315180991.

Carsten Stage. *Networked Cancer: Affect, Narrative and Measurement*. Cham, Switzerland: Palgrave Macmillan, 2017. Hardcover 978-3-319-51417-8. Ebook ISBN: 978-3-319-51418-5.

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These books address perennial questions: who is the self that becomes ill; how does illness generate new relations between that self and other persons; how does illness resituate the self in a body; and what are the boundaries of this body? *Autobiography of a Disease* (Anderson, 2017) reads like a novel; much dialogue, no citations. *Networked Cancer* (Stage, 2017) is a densely annotated scholarly monograph, drawing heavily upon and making a substantial contribution to studies of digitally mediated selves. The differences between these books show the vitality of contemporary narrative studies. Their crucial similarity is how both conceive of the self as *distributed*, an idea that is hardly new, but the material network of distribution has expanded in new ways. Selves and bodies become more intensively distributed through these networks.

Patrick Anderson is professor of performance studies, and his autoethnography seeks to perform in print a new mode of distributed narration. As I read, I imagined a stage monologue in which many voices emerge from one performer. Carsten Stage is professor of communications and culture, whose past work has been more about digital communication than about illness. He synthesizes a considerable corpus of recent studies of bodies and social media, redefining *affect* in the process. Reading Stage, I imagined a PowerPoint presentation, with each idea having a number of bullet points exploring its aspects.

For both Anderson and Stage, our modes of narration establish our relation to our worlds, and humans do lives in plural worlds. We are the subjects not only of *what* we narrate. That *what* is shaped by *how* we narrate. Although Marshall McLuhan (1967) receives no mention in either book, both, and more evidently Stage, read to me as the grandchildren of McLuhan. But the medium now is more than the message; it's the self itself, as that self is what is *enacted* in media that no person truly chooses, but each more or less artfully adapts. A narrational medium mediates both whom we can imagine ourselves to be, and whom we can be to others and with others.

Both books explore how media of narration differently centre or decentre the apparently singular voices of the narrator, as these media enable different relationships between narrator and those who receive the narration. What to call those recipients is not self-evident; neither *listeners* nor *readers* seems adequate, so I'll opt for *participants*, for reasons that should become increasingly clear. As Anderson evokes and as Stage describes how selves become distributed in narration, each book's specific interest in illness decentres. Ill people seem understood as one particular species of canary in either the specifically digital mineshaft, or in hospitals that are saturated with technologies of unthinkable sophistication, yet also mired in human fallibility. Seldom do I read books about illness in which the stakes seem higher not just for those who probably will, in the future, become ill, but for everyone, now, as everyone's life narrative becomes increasingly, intensively distributed.

Electronic Distributions of Ill Selves

In 2012, when I was writing the Afterword to the second edition of *The Wounded Storyteller* (Frank, 2013) and summarizing what had changed in almost 20 years, I noted the significance of possibilities for personal storytelling about illness that have been created by internet communication. I did not include any citations, because nothing I had read at that point seemed sufficiently compelling. Everybody agreed something important was happening, but nobody seemed to get at more than a fragment of what that was, and those fragments were in transition. Carsten Stage writes that he published his first article on social media and illness in 2013. He cites a number of studies written before then, but it may be only now that this body of work can be given the overall coherence that Stage manages to construct. Certainly, if I were writing my Afterword today, I would give *Networked Cancer* prominence. Stage gives careful, consistent attention to my own earlier work and to colleagues of that era. He then makes a convincing case that what's going on in electronic illness storytelling goes beyond the categories of illness narratives that we were both working within and bringing to articulation.

Stage's core contribution is his formulation of the *entrepreneurial narrative*, which on my reading blends a genre of narration with a social type of the sort that Georg Simmel (Levine, 1972) famously described early in the last

century (the stranger, the adventurer, the spendthrift, the miser, and so forth). Emphasizing the social type, Stage writes, “Being entrepreneurial means that you are able to pragmatically engage with existing means in order to build dynamic and revisable projects” (p. 63). Emphasizing narration, he writes that entrepreneurial narratives are “not only about connecting past, present, and future.” They also are “about creating a device to mobilize, convince and activate followers” (p. 13). Those devices take multiple forms, including what Stage calls “social network sites” (pp. 79–80) or SNSs. Social type and narration then blend. “The entrepreneurial narrative,” Stage writes, “is one prominent way that cancer becomes visible to a broader media public, because it resonates with broader cultural transformations creating more focus on self-optimization and biological self-monitoring, and because it seems to be more widespread among younger media producers” (p. 31). That phrase, “media producer,” might mark one of several generation gaps this book opens up. I find the label alienating, but most of those whom Stage writes about would probably embrace it as a self-description.

Stage seems to make good choices in the entrepreneurial narratives he discusses in detail; I qualify that statement because I don’t know, and it’s difficult for anyone to assert with confidence, which types of narrations might be excluded.¹ The narratives he focuses on have numerous differences from non-electronically mediated narratives, including both edited print material and interpersonal oral storytelling about illness. Notable to me, these narrations tell illness in almost real time, compared to the temporal delays and editorial sifting of print narrations. Second, responses appear almost instantly, giving the narrations a co-constructed quality. The public attention elicited by entrepreneurial narratives is precisely measurable through site analytics—the currency of “likes,” visits, and comments. Third, digital narrations are less concerned with constructing a coherent narrative out of initially chaotic events, and then bending that narrative toward finding a way of knowing and experiencing life that has learned to integrate bodily, institutional, and interpersonal breakdowns as part of life. Discovering the point of suffering is not the point. In Stage’s account, eliciting participation is the point.

The preeminent difference, to me, is that print illness narratives were about exploring values, as illness generated crises about which values count most in different people’s lives, and which values ought to count. When Stage emphasizes that entrepreneurial narrations are *value-making*, a phrase he uses continuously, *value* is a specific quantity. The primal value is quantified measures of attention to the site. On some sites, more altruistic values are also quantified; often sites seek to raise money for cancer charities and feature reports of monetary value produced in donations. Readers are reframed as

¹ For example, there is no discussion of personal storytelling on websites dedicated primarily to sharing medical information, such as DIPEX International.

visitors, whose visit is recorded and measured. Thus visitors become participants who are mobilized to the activity of giving, first their attention, then their comments, and possibly their money.

Two crucial words in Stage's subtitle are *affect* and *measurement*. Metrics of participation do more than passively measure who visits the site, how much time they spend, whether they comment, whether they act to increase the site's visibility, and whether they donate, if that is applicable. Crucially for Stage, metrics are *actors*, in the sense described by David Beers, whom Stage quotes at length: "We play with metrics and we are more often played by them. Metrics are a complex and prominent component of the social as they come to act on us and as we act according to their rules, boundaries, and limits" (p. 124). To use another of Stage's terms-of-art, metrics *fascinate*, and the fascination of participation measures becomes part of the narrative, as that narrative unfolds in real time. A significant part of any participant's fascination are the measures of collective participation to which their visit, comment, and/or donation contributes.

Stage's idea of *fascination* is specified—it eludes definition—through its linkage to what is perhaps his densest and most important idea, *affect*. "Fascination," he writes, "seems to describe a certain type of ambivalent affective-visual encounter between bodies or bodies and spaces/objects/images etc." (p. 121). Entrepreneurial narratives seek to arouse affect, and affect is both an immanent reward of participation and also an instigator of further action, such as donating to a cause, or simply registering a "like." In Stage's revisionist usage, *affect* is more than academic jargon for emotional engagement, although it retains that sense. In 1950s sociology, affect was individual. In Stage's world of mobile connectivity and instant response, *affect* is collective. Stage writes, "For me, 'affect theory' makes it possible to ask questions about how affects travel, how they mobilize/fixate collectivities and individuals ... how affects are involved in the unruliness and stabilization of the social more than being a type of reaction that we simply learn to perform" (p. 21). I appreciate the questions he asks here, but the concept of *affect* is being asked to do a lot of work; what travels, mobilizes and stabilizes is difficult to specify. On my reading of the ill persons' narrations and participants' comments that Stage quotes as his data, both narrators and participants have "simply learn[ed] to perform" (p. 21, quoted earlier) certain emotions. People's language and rhetoric are soon highly predictable, as Stage demonstrates using a word cloud (p. 88, Fig 3.2). The media have affected what counts as *affect*, although specifying that is devilishly difficult, which is why one neologism is often explained by another. Yet Stage also convinces me that there is more going on than the reproduction of a conventional rhetoric—although that is going on.

What Stage teaches me, in my words, is that understanding these narrations requires giving up much of what counted as analytic capital for both writers/tellers of previous illness narratives and for the reader/listener/interpreters of these narrations. What is said, the actual words

used and the sort of stories told, may often be predictable and banal, if judged by the standards of published illness narratives. But that's not the point. The point, as Stage writes at the beginning of his book, is how "the ill person, or relative [typically parent of a sick child], becomes the centre of larger *participatory processes* (for example in the case of crowdfunding money for research or treatment, or commemoration if the illness leads to death)" (pp. 2-3). *Affect* denotes both the energizing force of this participatory process and also whatever it is that participation metrics measure and reinforce. Thus, *affect* becomes a new form of mediated relation among and between *bodies*, but I will not discuss this significant aspect of Stage's argument. In brief, just as narrations become distributed on multiple sites, in different media (including descriptive words, images including selfies and medical images, including scans and x-rays, metrics of the site), so also bodies become distributed through devices on which blogs are written and participated in. A digital phenomenology of perception seems to be intimated in this argument.

In what is one of the very few poignantly arresting phrases quoted from a blog, Rosie Kilburn (1992-2011) writes about having cancer recur, saying that what she wants is to get "back to before everything became a bloody waiting game" (p. 162). That phrase, *bloody waiting game*, expresses much of what is profoundly demoralizing not about the disease itself, but about being a medical patient. Stage provides a theoretically rich analysis that takes off from this quotation, but the conclusion he reaches is understandable without that intervening discussion. "And this is exactly the role of blogging ... to ... stabilize the private life of the blogger and *eradicate permanent waiting*, while at the same time turn the blogger into a publicly active and entrepreneurial citizen" (p. 164; emphases added). He elaborates: "Blogging for Rosie becomes ... a means to turn her into a subject with a public project instead of a subject waiting for treatment for a private condition" (p. 164).

The politics of such narrations are "ambivalent" (p. 71), and in working out these ambivalences, Stage makes distinct contributions to governmentality theory and actor-network theory, among other scholarship he invokes. It's no surprise that entrepreneurial narrations have multiple dangers, to which Stage is attentive, although how these dangers will play out in time, nobody can say. But with those qualifications noted, what counts immediately is that Rosie finds some better way to live her life within the bloody waiting game, by mobilizing others to be there with her.

Back to Print, Differently

Lest we think that every ill person is narrating his or her illness on digital media in real time, it's useful to be reminded that if internet communications figure at all in Patrick Anderson's (2017) tale of extensive treatments for a massive bacterial infection, those mentions were too fleeting to remain in my memory. The acknowledgments say the book was written over a

period of ten years. The narration may be traditional in that gestation period, but Anderson has achieved, on my reading, something distinctively new. His own descriptive term for this narration is “evocative autoethnography” (p. 220), although he is not concerned with discussing how that differs from other forms of autoethnography, or even specifying what he considers autoethnography to be. He is very concerned with listening “for the native languages of the objects and beings that are now intimately part of me: the bacteria that thrived in my blood and tissues; the rods and pins that hold my skeleton together; and of course that tiny filter [surgically placed in Anderson’s interior vena cava] visible only as a shadow in the X-rays and sonograms performed ritually each year” (p. 221). His book takes seriously what he calls, following Karen Barad, the *agency* of “such matter [as] ‘active, responsive, generative, and articulate’” (p. 221). The agency of the tiny filter is never given its own voice, but in six “Interludes” of a couple of pages each, Anderson conjures the narrational voice of the bacteria, inviting them to tell their version of the story.

Published illness narratives from the 1970s to the present often juxtapose what the ill person/narrator has learned against the knowledge claimed by institutional medicine, personified in the characters of particular physicians and nurses. This experiential knowledge may be complementary to medical knowledge, or it may be oppositional. An opposition between lay and professional knowledges generates narrative tension in a contest for epistemic privilege; the ill person as narrator resists being known as medicine would know him or her. Anderson takes a meta-position when he writes that his narration seeks “to embrace the constant stream of disorientation, misrecognition, and radical undoing that occupies the very heart of illness ontology” (p. ix). In Anderson’s story, institutional medicine makes mistakes and it does some things that are extraordinary. Patients and their loved ones gain experience but never certainty; *no* agent enjoys any epistemic privilege. Doing without that tension between knowledges requires a different narrational voice.

Anderson seeks to tell a story in a way that “distributes the agency of narration—the power to describe—not just to the many human actors involved in treatment and care-taking, but also to the non-sentient beings involved in treatment and well-being” (p. ix).² Readers will probably vary in their perceptions of how far the book actually does that. Human actors still get most of the airtime. The sections in which bacteria speak remind us of what else is going on, and they subtly affect the tone of the whole, but readers’ reactions to what difference these passages make will probably vary.

What clearly does make a difference is Anderson’s decision to write in the third person. Thus it makes sense to refer to *Patrick* as the protagonist of the story and *Anderson* as the author of the book. The two-page Foreword and the

² Latour (1996), not cited by Anderson in his analytic Afterword, offers an earlier ethnographic experiment in letting a non-human agency speak. Stage does cite actor-network theory’s attention to the agency of non-human actors.

five-page Afterword are written in Anderson's academic voice. The intervening text (217 pp.) is a linear recounting of the ups and downs of Patrick's near-fatal infection and its ultimately successful treatment. We learn little about Patrick's life outside of illness (he is a graduate student, but we are not told what he studies; he's gay, but that identity is already established), and what we learn about him during illness is, mostly and at best, seen through the eyes of others. For example, the following passage begins from the perspective of Patrick's mother, Deidre, who is his main source of support and a vivid character in the story. Deidre's point of view then morphs to Patrick's embodiment; though her observing gaze, we seem to feel what he feels, forgetting that the passage is Anderson's writing. I choose this passage because it's both typical of Anderson's style and, to me, successfully evocative of being ill:

Deidre turned to look at him. She saw that something had changed: his face had relaxed in a troubling way; his eyes had lost focus, the muscles around them turned down like a frown. Like a lamp on a dimmer switch flickering at the lowest setting. Like a suit, off its hanger, crumpled on the floor. He reached for the wand that would deliver more pain meds into him, pressed its button. He closed his eyes, squeezed them shut, then released. He squeezed them again. A line of water spilled out from the right one, the most damaged one. It tipped round his cheek, then slid back to his neck, behind his ear. It seemed to dry simultaneously, as if in a desert, leaving only her knowledge that it had been there. (p. 55)

Anderson rarely editorializes; as I wrote, the story is told mostly through dialogue. The following passage is as close as he gets to a moment of author's message. But after nearly editorializing, the passage returns to the characters' voices:

They sat in silence, Patrick and his mother, wondering separately how strange it was, this disproportionate arrangement: most of the doctors were so disabled when it came to affection—or, really, human connection full-stop. And at the other end of the economic spectrum, holding so little power, the nurses seemed to understand their charges as part of a large extended family....

Patrick thought of these things and wondered at their place in the flow of things, marveled at their stupidity. Deidre wasn't surprised: in the long tail of history, after all, nurses had usually been women and doctors had usually been men. "Men screw everything up, to their own advantage," she thought, then added, "when women screw up, we *all* lose." (p. 83).

What is gained by calling this writing *autoethnography* is not clear to me; in academia, such labels legitimate, even when their descriptive specificity

seems low, and that legitimation has real institutional consequences. Anderson reports doing considerable research—both archival and interviewing—during the years he wrote the book. But novelists do research, and here, as in a novel, the research is folded invisibly into the storytelling. I found myself wishing the book were marketed not to an academic audience but to the common reader. It would be especially useful as a companion to people undergoing prolonged hospitalizations. The story has no turning points and Patrick comes to no great insights, but there is an accumulation of human connections in which people put themselves out in the quality of their caring for Patrick. Those people eventually include a couple of doctors, who exemplify the most caring acts of professional boundary crossing, showing that typifications never predict specific individuals. Patrick clearly has a gift for generating friendships. We readers are never told in what specific qualities that gift resides, but the book made me believe it. Good stories make us believers.

The story is about the varieties of human goodness enacted in care. That care can offset multiple forms of institutionalized indifference, most notably—this story being set in America—the onslaught and confusion of hospital bills and the anxiety those provoke, when disease has already made life anxious to the breaking point. Most valuably for me, the story is about the capacity to persevere. Patrick is in most senses passive during his treatment, but Anderson conveys what is consequentially active in this apparent passivity. My best word for that distinctive agency is *perseverance*. In his perseverance, Patrick makes himself a worthy companion to other suffering people who must keep holding on, uncertain whether that will have any payoff.

Entrepreneurial, or Not

It's good to live in a world that creates spaces for both Stage's entrepreneurial narrations and Anderson's story, which if it is not a memoir, shares the general qualities that Stage attributes to the memoir genre. Anderson is not trying to mobilize anyone. The companionship he offers is at a greater distance, without measures or metrics. His publication medium provides no space for the reader's immediate commentary, thus forcing reactions to be more reflective. Anderson invites readers to stay with his narrational voice—his performance style—over a period of time, and then perhaps they will find themselves narrating their own lives in something like his third-person voice. Emotional states are rarely named, claimed or attributed. Rather, the quality of affect is observed in actions: one physician simply walks out of the room when the conversation veers toward the possibility of Patrick's death, and another sits with him, mostly silently, for thirty minutes while the effects of a surgical procedure gradually mitigate. Anderson is a finely observant storyteller, telling a story in which he, Patrick, is the focal point, but it's never *his* story. Perhaps that is all the definition of autoethnography we need.

Both these books step outside the forms of narration that I identified and described in the 1990s, although those narrative forms persist, embedded in the new narrations, as Stage notes specifically. Reentering the world of illness through these books, I am left reflecting on how the possibilities of experiencing illness through multiple narrative media have expanded far faster than changes in how healthcare institutions are able to imagine treating their patients. It may be endemic to professions and institutions to be perpetually playing catch up. These books underscore how much catching up there is to do.

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