

## 8. Illness narratives: from analysis to answerability

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### INTRODUCTION

In a volume such as this one, it matters to include one chapter that presents people who are ill expressing themselves in their own terms: not as subjects of healthcare—not as *patients*—and not as participants in research, but describing their lives according to what counts for them, in narratives told as they choose to tell them. But social science immediately rushes back in. We the authors of this chapter mediate the writings of the ill, choosing whom to quote and framing what we allow writers to say: we tell a fragmented story of them telling their often fragmented stories. In doing this, it's both an advantage and a source of bias that we ourselves have written either a full memoir of illness (Frank 1991/2003) or a research study containing a considerable amount of first-person illness experience (Spencer, 2021a). We thus approach illness narratives as both participants in such writing and observers of it. And then the texts of the narratives themselves are mediated in multiple ways, including expectations of publishers, as writers initially anticipate and later respond to demands of publishing.

These complications reflect what is at stake in writing a memoir of illness: how do ill persons, as writers, reclaim experience from the multiple voices that presume to speak for ill people? These are principally voices of professional healthcare and family voices, but the circle expands, especially with the proliferation of Internet sites that present people's illness stories in ways more or less defined by the site's templates. Nor are illness narratives unified as to whom these reclaimed voices are addressed to, or what response the writer wants. Many, perhaps most, writers of illness narratives are themselves uncertain about these questions. Keeping that uncertainty in the foreground, rather than seeking to resolve it, seems to us to be a responsibility of those writing about illness narratives. Methodological questions shade into ethical issues. We see both as concerning *presumption*: when are we presuming, or if, in analytic writing, some presumption is inevitable, how far should we presume?

A one-word response to this cluster of questions is that illness narratives demand their reader or commentator be *answerable* to them. We take the term answerability from the literary theorist Mikhail Bakhtin (1919/1990).<sup>1</sup> Answerability means that author and reader are in a relationship of dialogue: each is open to be changed by the response of the other, and each expects the other can and will change. In dialogue, unlike the aspirations of some versions of both social science and clinical practice, there is *no last word* about persons. Answerability, as we use the term, is a demand to continually question the terms in which the other, whether that is a person or a text, expects to be responded to: what form should that response take? But we again emphasise that the writer's expectation for answerability is itself always uncertain, open to be reshaped in the process of dialogue.

Finally, in dialogical relations of answerability, who we are to the other is also who we are to ourselves. There is no stance of third-person detachment. Thus in this chapter,

first-, second-, and third-person voices mix and meld, with fuzzy boundaries between them. Far from apologising for this mixing of voices, we claim it as one necessary beginning place.

The form of this chapter reflects the issues we have just sketched. We make no attempt at presenting a representative sample of illness narratives. Given the proliferation of narratives in media that include graphic novels, blogs, art installations, and performance art, how to imagine a representative sample eludes us. Instead, we begin with the briefest overview of how illness narratives emerged as a genre. We then focus on two narratives from different decades: Audre Lorde's 1980 *The Cancer Journals* and Anne Boyer's 2019 *The Undying*. Lorde's book is among the most cited in discussions of the genre; Boyer won the 2019 Pulitzer Prize and may become as frequently cited. Boyer is also self-conscious of writing after Lorde, reflecting on what they share and the distance between them.

Our discussion of each book takes the form of a dialogue in which we each seek to enter into responsive relationships with each book and with each other.<sup>2</sup> We consider it more useful to exemplify answerability rather than define it, and if our experiments at dialogue are only variably successful, what counts is how they open up possibilities for relating to these texts. We then shift our attention to the particular sub-genre of physicians writing about their own illnesses. In a *Handbook* concerned with healthcare, physician narratives claim a particular niche. Physician writers confront the same illness issues anyone does, but as they see themselves reflected in how clinical staff treat them, they are led to confront how they have acted toward their own patients. Physicians-as-patients enjoy certain privileges, but they also bear distinctive burdens.

## A BRIEF HISTORY OF A GENRE

This chapter examines illness narratives within roughly the past 50 years when scattered memoirs in which illness somehow figured became a genre. Historically, first-person narratives focused on illness were rare. Virginia Woolf, writing in 1925, spoke to this paucity, arguably overemphasising the degree to which literature omitted illness. Woolf wrote that we all

must go through the whole unending procession of changes, heat or cold, comfort and discomfort, hunger and satisfaction, health and illness, until there comes the inevitable catastrophe; the body smashes itself to smithereens ... But of all this daily drama of the body there is no record. (2012: 5)

There are indeed records—from Thucydides' account of the Plague of Athens in 430 BCE to Frances Burney's harrowing and much-quoted description of her mastectomy in 1811 (1995). Yet Ann Jurecic correctly notes that although five percent of the world's population perished in the 1918–19 influenza pandemic, it is “virtually absent from American and British literature of its era” (2012: 1). Part of the disconnection is what counts as “literature” and what becomes narratives. The lack of attention that Woolf and Jurecic identify seems to refer to authors writing from the subjective stance of being ill and making that illness central to understanding the whole of their lives—the main event of those lives.

The contemporary illness narrative might be said to have begun with Stewart Alsop's 1973 *Stay of Execution* and Cornelius and Kathryn Morgan Ryan's 1979 *A Very Private Battle*. Both Alsop and Cornelius Ryan were prominent public intellectuals: Alsop as a

political journalist and Ryan as the writer of best-selling histories of World War II. Each wrote about his illness in terms that were, if not confessional, bluntly explicit about the effects of their respective illnesses on their bodies and about the issues and conflicts that illness created in their lives. Both wrote in the expectation that cancer would kill them, and each book is a coming to grips with death. Thus both broke a pervasive silence about illness, its effects, and confronting mortality. Each also viewed medicine with a critical eye, making their physicians the subjects of their evaluative gaze. Each weighs what their physicians can see and what is beyond their horizon of concern. Each writer is keeping his own chart of his physicians' progress through illness.

Towards the close of the 20th century in the U.S., illness narratives became more widely prevalent and disseminated, further catalyzed by the political exigency of the HIV-AIDS epidemic of the 1980s and 90s which produced, as Jurecic describes, a "thunderous cacophony of voices" (2012: 2). Many of the books that gave illness narratives public recognisability—and convinced publishers to take an interest in such manuscripts—were by writers who enjoyed some renown, often as actors. Celebrity narratives—many of which we read with respect—created a market. Frank's 1991 *At the Will of the Body* was possibly the first illness narrative from a major publishing house, Houghton Mifflin, by a first-time author with no other claim to public attention. A further shift happened in the early 2000s when university presses began to include illness narratives in their lists. Most recently, books such as Julie Yip-Williams's *The Unwinding of the Miracle* have been met with a wide readership already generated by the author's blog. When published posthumously, the book became an immediate bestseller. *The Unwinding* exemplifies the narrational multiplicity of published illness narratives: they report the author's experience, but how they report is already shaped by how others have reported; published narratives then shape readers' expectations for their own experiences. Reading such books, we ask both what resources enable authors to tell their stories as they do, and also how their narrations affect how readers experience illness, either at present or in the future. The relationships are multi-sided and mobile.

What counts for us is how, going back to Alsop and Ryan, illness narratives are written by writers who use illness as a perspective from which to reflect on a range of experiences that include but are not limited to occupying the patient role. One trend we observe is toward paying less attention to medical treatment; the more recent the narrative, the more likely that clinical staff will be only fleeting presences. At the extreme, the writer's diagnosis is never specified, which we take as a significant message about what we, the readers, are supposed to be paying attention to. We thus emphatically reject the descriptive terms "patient narratives" and "pathography" as being contradictory to the intentions of those who write these narratives. Illness narratives do usually give some attention to what's experienced while inhabiting the patient role, but they do not assimilate the identity stance of being ill to being a patient, with that word's implicit connotation of passivity. The neologism "pathography" foregrounds the availability of the narrative to and for medical appraisal and edification. Some ill people may want clinicians to read their stories and be affected by them—and perhaps to change how they relate to the individuals to whom they offer care—but that should not position healthcare professionals as privileged mediators of the value of illness narratives, nor should the narratives be reduced to such instrumental utility for clinicians. As we began by saying, these narratives are written to reclaim a voice that has been appropriated by professionals and to make those professionals the subjects of its gaze—or to leave them on the cutting room floor.<sup>3</sup>

AUDRE LORDE: *THE CANCER JOURNALS*

**AF:** I feel like writing “Dear Audre,” because her/your work speaks to me directly, drawing me into a dialogue that has now lasted three decades.

To go back to the beginning of my relationship to this book, it’s important for the understanding of first-person illness narratives that simply getting a copy of *The Cancer Journals* wasn’t straightforward in the early 90s. I’d heard about Lorde’s book a long time before I found a small feminist independent bookstore in downtown Calgary that would order it for me. The publisher, Spinsters/Aunt Lute, had limited distribution. Holding a copy, when it finally arrived, felt like a hard-won treasure; that speaks to how times have changed.

My reading was continually interrupted by my compulsion to run to wherever my wife was and read a passage to her. She’d stop and look at me, hearing it, and we both felt like somebody out there had experienced cancer the way we had. That connection is what illness narratives, memoirs, *are*. One person finds, in another’s words, a capacity to recognise and articulate experiences that could not be spoken.

The line that spoke to us first was: “Your silence will not protect you” (p. 20). There had been so many silences during my cancer, and even more during the months between my mother-in-law coming out of her last remission and her death. So many silences, and far from anyone being protected, relationships were fractured by those silences. Some finally were repaired, others never were. On our account Lorde could have said: Your silence will corrupt you, impairing your life worse than the effects of disease itself.

The work of memoir truly is “reclaiming of that language which has been made to work against us” (p. 22). Has anyone since Lorde ever claimed so compellingly her right to speak, to fill the silences with her need to use language to speak of what happens truly? The question she raises is crucial: what are the languages that work against ill persons and their families? We need a list, possibly beginning with medical languages, then extending to all sorts of evocations of health.

When I read *The Cancer Journals*, I had finished my memoir *At the Will of the Body* and was unsure what followed. Alongside what Lorde said about silence, what she said about work was crucial to me. Her non-rhetorical question, “because I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?” (p. 21), went straight into me. Thirty years later, it’s what I still ask myself: am I doing the work that I, given who I am, can do? Lorde’s demand that her readers be answerable is direct.

Cancer on Lorde’s account is not an experience, as in “the patient experience.” It’s a calling to a work. Are you doing yours? Albert Schweitzer wrote, after his own critical illness following World War I, of the fellowship of those who bear the mark of pain. Lorde would, I think, have understood that phrase, and Schweitzer would have understood what she meant by work.

Anatole Broyard observes that doctors discourage our stories (p. 52). Lorde would expand the scope and raise the intensity of that. The point of her most specific stories—especially how a nurse demanded she wear a prosthesis, a “form” (pp. 58-9)—is that medicine disciplines patients to participate in enacting a particular narrative, which I later called the restitution narrative. For Lorde, that narrative legitimates the demand to consider breast cancer as a problem of public appearance, and that problem is readily solved with the proper prosthesis. “Her message was, you are just as good as you were before, because you look exactly the same” (p. 42). That’s written about a Reach for Recovery volunteer, whom Lorde sort of likes personally but who represents a toxic narrative. The nurse is more explicit when she tells

Lorde, “Otherwise [not wearing a form] is bad for the morale of the office” (p. 59). Here is a paradigm example of how healthcare workers impose their needs on patients by redefining those as the patients’ needs. The nurse’s speech is language being made to work against Lorde, generating her need to reclaim a language of her own. Whatever my sociological reservations about how far any language can ever be “our own,” Lorde sweeps those aside; she compels me to believe she speaks for herself.

Lorde challenges me to ask how we, her scholastic readers variously located in health research, social science, and health humanities, should be answerable to her writing. Our work, in response to her work, seems to be this: How do we help ill people’s narratives do their work of reclaiming experience in the person’s own terms, which is often reclaiming from institutional medicine? In particular, how far is it possible for healthcare to recognise the dimension of illness that lies beyond the disease, what Lorde calls “the whole terrible meaning of mortality as both weapon and power” (53)? Doctors don’t just discourage stories. The whole healthcare complex is organised to blunt the need to reclaim language that Lorde is pointing toward, and research often colludes in that. That blunting is enacted in the nurse’s demand to wear a prosthesis. It’s the point of waiting rooms: not only to optimise physicians’ time by having patients always ready, but to induce passivity in those patients by wearing them down, teaching them to devalue their time, to be the supporting actors who sometimes come on stage to be a foil to the lead, but mostly sit waiting in the wings.

Lorde’s line, “In order to keep myself available to myself” (p. 65) is for me a found version of a Zen kōan. What does it mean, to be available to yourself; who is that *you*? Lorde recognises this complexity early in her book when she asks herself: “And which me was that again anyway?” (p. 24). There is never a singular self, transparently self-knowing. But, that doesn’t mean that people should cease asking whether they are available to themselves and in what currency is availability attained. For Lorde, the currency of friendship seems primary: she knows herself as she lives among women. But knowledge also requires the currency of written words, the production of which is her work. Her circle then expands to others of us who ask her questions, seeking to participate in her work.

Here’s a tentative definition of the work of memoir: As the author makes themselves available to themselves, the effect is to allow readers greater availability to themselves. Lorde reminds me, all these decades later, what it was about, what the work should be, and what remains.

**DS:** I first read *The Cancer Journals* as an assigned text in an “Illness and Disability Narratives” course in 2011. The very existence and increasing prevalence of such courses—when there was not appreciably a genre to study at the time this text was written—speaks to its power. The Aunt Lute Books Special Edition I purchased wasn’t hard to come by as it was for Art, as it was by then a canonical text. Yet it still stood apart from the rest of the titles on my illness narratives bookshelf in its candour and directness. As in the first edition, a photograph of Lorde’s face fills the cover; she is smiling, in the sunshine, and looking directly at the camera/viewer/reader (Lorde, 2006). As Elizabeth Alexander notes, “here she makes herself, her body, empirical, the best evidence of her arguments and self-definitions. She illustrates that she is all she proclaims herself to be—fat and black and beautiful—but that cover is also a strange testament to her very physical existence: she is a survivor and alive” (1994: 702).

As one of these readers, I feel Lorde’s presence palpably. The introduction begins in the third person: “Each woman responds to the crisis that breast cancer brings to her life ...” and in the second paragraph shifts to first person: “I am a post-mastectomy woman who believes

our feelings need voice in order to be recognized, respected, and of use” (p. 9). The shift from third- to first-person enacts the shift from the objectifying gaze towards illness to that of direct lived experience and testimony. In offering her testimony, Lorde makes an explicit claim for acknowledgement, in hopes that doing so will benefit others.

Crucially, Lorde also situates herself in her intersectional identities—as (in one articulation, among many) a “black lesbian feminist mother lover poet” (p. 25). Agency, empowerment, disempowerment, suffering, joy—these lived experiences are not abstractions, but are lived and embodied, made present throughout her work. The situated qualities of her own experience are specific to her; and that singularity extends, in direct address, to you, the Reader, who will have your own specific lived experience, challenges, and duties. The passage Art cites above—“because I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?” is preceded by a series of questions: “What are the words you do not yet have? What do you need to say? What are the tyrannies you swallow day by day and attempt to make your own, until you will sicken and die of them, still in silence?” As Art puts it, these are *not* rhetorical questions. We are jolted *out* of rhetoric and abstractions. She does not hide behind “the mask of prosthesis or the dangerous fantasy of reconstruction,” as she finds these to be tools of silencing. Wake up! Speak! “Your silence will not protect you.” She means *you*.

While these are not rhetorical questions, Lorde’s direct expression of her situated, embodied experience is a forceful rhetorical and advocational strategy, shared with many writers addressing issues of race and gender, among other themes, and it remains an important aspect of the genre of illness narratives. It is a riposte against what Marilyn Frye calls “The Religion of Knowledge.”<sup>24</sup> The *personalising writer* thus works against the invisible agentless passive voice of the clinic note, e.g. “the procedure was attempted.”<sup>25</sup> This is a key means by which Lorde’s narrative emphatically succeeds in shifting from the medico-centric view of the ill person.

*The Cancer Journals* was first published in 1980. In 1984 Lorde learned that the cancer had returned, metastasising to her liver. On December 9, 1985, she wrote: “I am going to write fire until it comes out my ears, my eyes, my noseholes—everywhere. Until it’s every breath I breathe. I’m going to go out like a fucking meteor!” (2017: 71).

## ANNE BOYER: *THE UNDYING*

**DS:** Anne Boyer’s *The Undying* was published in 2019, nearly 40 years after *The Cancer Journals*. While each is its own singular account, putting these works side by side offers the opportunity to consider the evolution of the genre. Indeed, while Lorde had few forbears, Boyer immediately situates her account in relation to other writers, including Lorde, Susan Sontag, Kathy Acker, and Eve Sedgwick. She notes the evolution from Sontag’s 1978 *Illness as Metaphor* to Lorde, noting that, “unlike Sontag, Lorde uses the words ‘I’ and ‘cancer’ together” (2019: 4).

Boyer, too, writes in the first person. She begins:

When the technician leaves the room, I turn my head toward the screen to interpret any neoplasms, the webs of nerves, the small lit fonts in which my pathology and/or future or future end might be written. The first tumor I ever saw was a darkness on that screen, round with a long craggy finger jutting from it. I took a photo of it from my exam table with an iPhone. That tumor was my own. (p. 13)

She places us—me, you—into the room with her, at the moment of seeing, spying the tumour, taking her own image, claiming it, and claiming it in language. These questions of representation—the very *possibility* of giving an account of her illness, and of what sort of *form* it can take—are ones Boyer highlights and weaves throughout her account. As she writes in the Prologue, “breast cancer is a disease that presents itself as a disordering question of form” (p. 7). Boyer’s account is one that resists the trope of the triumphant restitution narrative, and offers a response to the plea for “not clichés but an acknowledgement that illness is not simply an opportunity for personal growth but a soul-wrenching encounter with loss, limitation, and the reality of death,” as scholar and cancer survivor Kathlyn Conway puts it (2013: 2). In describing such illness narratives, Conway points out that they

not only push the boundaries of what we can understand about illness and disability, but also describe their confrontation with the limits of language and literary form for representing pain, suffering, and awareness of mortality ... Even as these writers find language and form for their experience, they discover that something of its emotional intensity slips away in the telling of their story. Still, their attempts are invaluable; they marshal all their resources of intellect, will, and humor to face, and allow us to face, the limits of the self and its expression in language. (p. 3)

Boyer explicitly wrestles with the conventions and limits of language and literary form. Her account is written in short, sometimes fragmentary sections. Some read as prose poetry. This format bears some relation to the diaristic form of *The Cancer Journals*. It also reminds me of a conversation I had a few months ago with a young writer whose husband died suddenly and unexpectedly last year. She explained that particularly in the first months after his death, she could not read and concentrate for the length of a standard book chapter, and so in writing about her own grief and loss, she wished to do so in a way that would be more accessible to readers in a similar state—a non-linear text with shorter sections, so that there are multiple points of entry.

Boyer notes that the challenges have changed, from the time of Lorde’s writing to hers: “The silence around breast cancer that Lorde once wrote into is now the din of breast cancer’s extraordinary production of language” (p. 8). Speaking to this din, Barbara Ehrenreich’s 2001 “Welcome to Cancerland” describes her own experience with breast cancer and its transformation from a hidden, shameful secret to “the biggest disease on the cultural map” with cult-like proliferation of redemptive cheerful testimonials of personal transformation and growth. “Everything in mainstream breast-cancer culture serves,” she writes, “no doubt inadvertently, to tame and normalize the disease,” and she suggests that the effect—garnished by pink ribbons and teddy bears—is infantilising, distracting us from the environmental causes of the disease (pp. 45, 49). Similarly, Boyer describes this prescriptive restitution narrative and its attendant cultural apparatus: “To tell the story of one’s own breast cancer is supposed to be to tell a story of ‘surviving’ via neoliberal self-management—the narrative is of the atomized individual done right, self-examined and mammogrammed, of disease cured with compliance, 5K runs, organic green smoothies, and positive thought” (p. 9). Thus in contrast to Lorde’s era, now “the challenge is not to speak into the silence, but to learn to form a resistance to the often obliterating noise” (p. 8).

Once it becomes possible and anticipated to offer an illness narrative, then certain narrative arcs and tropes become expected, and Boyer explicitly wrestles with this tension even as she pens her own account: “I do not want to tell the story of cancer in the way that I have been taught to tell it” (p. 115). If Lorde’s meta-message was to be the messenger—against

all pressure to remain silent—Boyer is oppressed not by silence per se but by the limits of language and the limitations of an expected triumphant illness narrative. While Lorde's and Boyer's strategies differ, both write as a form of resistance, centring their own experience.

**AF:** Because Boyer writes in fragments, it's sentences that stick in my memory; she tells remarkably few stories. One such sentence is what Danielle quotes about the "din of breast cancer's extraordinary production of language." It is worth adding the sentence that precedes and sets up that one: "At least in an age of 'awareness,' ... what we are told must be given up for the common good is not so much one's life as one's life story" (p. 8). As power once demanded silence—and normal appearance—it can just as well demand "awareness," or specifically a story in which the self is offered up. Boyer writes on the razor's edge between responding to the need that Lorde identified as keeping herself available to herself, with her stories being the media of that availability, and the perpetual cooptation of story into the product marketed by the commercialised culture that Ehrenreich described (see also King, 2008). For Boyer, keeping herself available means resisting telling her story in a way that would fit what she believes others expect her to represent. The nurse who demanded Lorde wear a form in order to sustain the morale of the office has become a far more generalised demand to proclaim cancer as ... and here a number of predicates can be filled in. Boyer calls it becoming "the angel of epiphany" (p. 115) that is expected, even demanded, by those whom she calls the "anti-sadness reactionaries" (p. 206). "Literature," she writes, "sails along on every existing prejudice" (p. 115), leaving me wondering how much social scientific health research she would characterise as reinforcing, not dismantling, existing prejudices. The work, in Lorde's sense, is to make visible those prejudices, asking whom they serve.

"After cancer," Boyer writes, "my writing felt given its full permission" (p. 283). For those who study healthcare, she presents a challenge: do you give your research participants full permission? There are so many ways to cue people's responses, giving permission to tell only the expected story. Should we read Boyer critiquing social science when she writes: "The common struggle gets pushed through the sieve of what forms we have to make its account, and before you know it, the wide and shared suffering of this world is narrowed and gossamer, as thin as silk, and looking as special as the language it takes to tell it" (p. 115). Can we who write about illness experience read that without feeling some guilt?

Boyer's other sentence that sticks with me is when she writes: "and if I live another forty-one years to avenge what has happened it still won't be enough" (p. 167). Peer support groups, in my observation (Frank, 2012), would disallow a word like *avenge*; nor do I see anger being reported in health research on illness experience. Boyer calls out the collusion of multiple institutional means—from comments made during bedside care through peer support to health research—that cool out the anger that attends being ill generally and being a patient specifically. In his seminal article in 1952, the sociologist Erving Goffman (1997) adopted the jargon of confidence games—swindles that depend on the victim, or mark, developing confidence in the person doing the conning—to explore how institutions get people to accept losses. The "cooler" is the member of the con team who remains behind to convince the mark that pursuing vengeance would be against their best interest. Goffman enlarges this principle, suggesting multiple forms of cooling out, whether from job loss or injury from medical error. Boyer refuses to be cooled out: for her, another 41 years will not be enough to *avenge* what has happened.

The specifics of what must be avenged range from her brutal discharge from hospital the same day that she has had a double radical mastectomy, through her need to return to work far



too soon in order to maintain her health insurance, to the din in which she has to find a way to write her story against what is expected of such a story. Audre Lorde, Boyer laments (p. 155), was able to spend five days in the hospital, recovering from surgery. Then again, Boyer finds a major publisher and wins a major prize. But I imagine for her, neither is enough.

## MD AS PATIENT

Clinician writing contains some elements in common with illness narratives written by non-clinicians; but the differences also point toward broader questions about the potentiality of illness narratives.

When clinicians become ill they combine roles, newly experiencing their own embodiment and vulnerability. Often the roles are in conflict, as when physician Rana Awdish experienced severe abdominal pain during her pregnancy. As she recounts in *In Shock: My Journey from Death to Recovery and the Redemptive Power of Hope*, she, now a patient, is sent to the maternity ward, though she as a physician knows that she urgently requires surgical assessment. While non-clinician illness narratives often struggle against form, as in Boyer's account—the imperative to express that which cannot be expressed, or can only be expressed in the body—the physician-as-patient tends to resolve into a lesson learned of humility and greater caring, with the illness experience folded back into a re-formed and reformed physician identity (Spencer, 2021b).

Like illness narratives, physician memoirs are (with some notable exceptions) a relatively recent phenomenon. “Dr. X’s” 1965 *Intern*, a behind-the-scenes diary of a young physician during his internship, featured an anonymous physician on the cover, masked and in sunglasses, suggesting the forbidden and secretive nature of such accounts. Yet recent decades have brought a flood of physician memoirs, often focused on the gruelling years of medical training. They typically follow a narrative arc from idealism through a bewildering initiation phase and then on to disillusionment. A predictable turning point occurs when the physician (or someone close to them) becomes ill, often gaining greater understanding and sensitivity in the process.<sup>6</sup> One example of such an epiphany occurs when physician-writer Rafael Campo's feelings of revulsion towards an AIDS patient are altered after Campo himself suffers a needle stick while placing an IV on another AIDS patient. As he tends to his own wound, he muses:

I finally knew how human I was, I was made acutely aware in one terrible moment that all any of us has in the world is the same body ... What was happening ... felt like an opening, a revelation, a chance for survival ... Perhaps in the possibility of dying of AIDS myself, I could realize finally and fully for empathy. (2008: 93–94)

Here the author's experience of physical vulnerability offers a corrective to his lack of understanding, and a restoration of the call to care.<sup>7</sup>

While there is some variation, these epiphanies arise predictably as plot points in the genre. Awdish's 2017 *In Shock* is a recent example in which the experience takes centre stage, as she chronicles her own severe illness and near-death experience. In the introduction she sets the stage, explaining that

I had distanced myself from my patients the way I had been instructed to do in training ... until my own experience as a patient, I didn't allow myself to envision an alternative where I was unguarded, receptive, and freely giving of myself. I didn't understand that open channels would replenish my supply of self. That there was reciprocity in empathy. Luckily, I had the chance to die. (p. 10)

Awdish's experience of "dying"—her heart stopping in the OR, organ systems shut down, hearing the anesthesiologist saying, "we're losing her," and watching the scene from above—offers insights she would not have otherwise gained.

The dying physician is the apotheosis of the physician-as-patient trope, and the notable contemporary exemplar is Paul Kalanithi's posthumous 2016 *When Breath Becomes Air*. It begins as a fairly standard medical *bildungsroman* tracing the formation of professional identity, with the first section titled, "In Perfect Health I Begin"—health aligned with his assumption of the role of the physician. Towards the end of his neurosurgery residency, however, Kalanithi is diagnosed with cancer, and the incommensurability of his identity as both doctor and patient is a recurrent theme. For example, when he checks into a hospital room where he had treated many patients and the nurse informs him that "the doctor will be in soon," he notes the reversal: "And with that, the future I had imagined, the one just about to be realized, the culmination of decades of striving, evaporated" (p. 16). Reviewing his own scan, he toggles between the roles of clinician and patient, the latter seemingly overwriting the former. The opening to Part II, "Cease Not till Death," begins: "Lying next to [my wife] Lucy in the hospital bed, both of us crying, the CT scan images still glowing on the computer screen, that identity as a physician—my identity—no longer mattered" (p. 119). He returns to his work, and when his illness intensifies after a pause in working, he notes the incompatibility of the roles, observing that "like a runner crossing the finish line only to collapse, without that duty to care for the ill pushing me forward, I became an invalid" (p. 125). While occupying the patient role offers Kalanithi valuable insights—"As a doctor, you have a sense of what it's like to be sick, but until you've gone through it yourself, you don't really know" (140)—he does not have the opportunity to metabolise these lessons over time and reconcile with his role as a physician. His life—and its narration—are truncated too soon. Whether he could have reconciled these roles, given time, remains unanswered; and we are left with a broader question: are they reconcilable?

In some examples, the effect of illness on the writer's identity provokes a fundamental re-composition, as in Awdish's case. Likening medical school to "a secret society," she recounts that

the forward progression through residency and fellowship was nothing more than a comfortable lie my body would ultimately dismantle ... I would experience an illness—followed by a long, painful, recovery—that took me apart, piece by piece, and *put me back together in a conformation so different I questioned if I still existed at all*. (p. 2, emphasis added)

But in most of these works, the disruption and epiphany of illness is re-absorbed into the physician role, without further disruption. Psychiatrist and bioethicist Robert Klitzman discusses this orientation toward professional identity in *When Doctors Become Patients*, noting that "medical students identify first with patients, and only later with fellow physicians. Medical training radically challenges these trainees, taking them apart psychologically, wounding

them. They must then *put themselves back together*, and end up identifying with fellow doctors” (2008: 34, emphasis added). And in describing the experience of physician illness in a chapter entitled “Between Two Worlds: Physicians as Patients,” anthropologist and epidemiologist Robert Hahn describes the impetus of ill physicians to “relay to their colleagues a vital message about patienthood, a message from ‘the other side’”; and the last stage of the ill physician’s narrative is one in which “they reformulate their theory and practice of medicine in the light of their patienthood,” essentially absorbing the lessons back into their professional identity (1995: 236, 258).<sup>8</sup>

The move to put the professional mask back on after visiting the land of patient-hood is not typically explicitly acknowledged. Often there is at least some gesture towards greater awareness, but lacking description of action or proposals for specific reforms to back it up. For example, Klitzman’s *When Doctors Become Patients* tells of many such realisations amongst his physician subjects, as when Roxanne notes that “I can call up whomever I want and solicit expert advice ... Yet even for me, sometimes it’s hard to get information, and I know whom to ask. So I can’t imagine what it’s like for some patients ‘out there’” (p. 41)—but no musings about how to improve information access for those “out there” patients. Dan, an oncologist with cancer, “insisted on wearing surgical scrubs rather than patient pyjamas ‘... it’s very strange to sit there in a hospital gown with my butt hanging out’”—but no thought of providing more dignified patient gowns (p. 42). Harry, who has been in practice for several decades but has experienced interminable wait times as a patient, now asks, “Why should anyone have to wait around?” (p. 118)—indeed! And we could add another query: why wasn’t this question apparent to him before? Perhaps because—as Art describes above—ritualised waiting induces passivity and compliance, so without the empowerment of the doctor-turned-patient, it isn’t even articulated. And again, where is the call to change?

If illness narratives interrogate form and function as sites of *resistance*, clinician memoir evinces the fact that such resistance does indeed threaten the medicalisation of the illness experience, the flattening of the teller to the tale, the flattening of the tale to data. Awdish and Kalanithi are outliers to this trend; Awdish devotes considerable effort to reforming medical training, and offers a very practical “We Can Do Better—Communication Tips” for physicians and patients at the end of her memoir; and Kalanithi’s narrative is cut short before it might resolve into a standard physician memoir. Coincidentally, their illnesses were so grave that they were both brought to the threshold of death (and beyond, in Kalanithi’s case). Perhaps they point toward a way forward?

## INCONCLUSIVE CONCLUSIONS

Because this *Handbook* is intended primarily for an academic readership, a question on which to conclude is how healthcare researchers can read illness narratives. Because researchers get sick too, they might read them as anyone does: to find out how those who have gone through this before have found their way, or ways. That reading may be truest to the authors’ intentions.

If these books are read in the context of research projects, they can set the agenda of that research. First-person narratives can teach the researcher what to look for, how to ask the right questions, and most important, *what counts* for ill people, as opposed to medical professional interests. It’s easy for qualitative health researchers to form collegial relationships with healthcare professionals and then take for granted those professionals’ sense of relevance: what

the professional enterprise considers worth finding out. Reading illness narratives reminds researchers that ill people have their own perspective, and they have insights into institutions and their processes.

Reading illness narratives mid-way in a research project has complementary uses. Such a reading can raise questions about what is not yet being heard or observed, and thus suggest a reorientation of data collection to make research open to issues that illness narratives raise but that have not yet shown up in observations. As Boyer writes that only after cancer does she feel she has full permission to write, her narrative raises the possibly uncomfortable question of whether the researcher is giving participants full permission to express what counts for them.

But both these readings involve researchers *using* illness narratives. We return to what is perhaps our main argument: to use a narrative risks being only minimally answerable to it. Making use of is not inherently wrong, but it is an incomplete response, failing to engage in dialogue. At worst, reading-for-use imposes its purposes on writers, denying what is already complete in their work. That line of thinking leads to the uncomfortable question of whether it may be euphemistic to speak of research participants: who sets the terms of participation?

Our modest proposal is that if research relationships call for an ethic of answerability, then first-person narratives should be read as the *conscience* of research. Writers of illness narratives make public their suffering; they ask that what happened to them be witnessed from their perspective. In one of Boyer's most fully developed stories, she describes a minor revolt in the chemotherapy infusion room when a man tells a nurse that inserting a needle hurts (p. 224). The nurse denies that the procedure hurts. Other voices then join their fellow patient, affirming that *It hurts*. That story is a microcosm of what illness narratives can do: they affirm an experiential reality that is at best neglected and at worst denied, and that affirmation builds a sense of fellowship.

Institutional research ethics focuses on what can be called an injury/liability model. Certain negative rights are ascribed to participants—the right to anonymity is most basic—and research is responsible for not injuring the participants by infringing on that right-not-to. Answerability imagines affirmative rights: in Boyer's story, the right to be heard saying it hurts. As the conscience of healthcare research, illness narratives ask whose experience are being given full permission, and how what is heard is then represented, as the research is filtered into its public form.

Thus we give the last word to a repetition of Audre Lorde's question: "because I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?" (p. 21).

## NOTES

1. "I have to answer with my own life for what I have experienced and understood in art, so that everything I have experienced and understood would not remain ineffectual in my life." Bakhtin then emphasises that answerability is dialogical, cutting both ways: "It is not only mutual answerability that art and life must assume, but mutual liability to blame" (1990, p. 1).
2. The dialogue between us as co-authors began while teaching a graduate seminar on illness narratives in Columbia University's Program in Narrative Medicine, Spring Term, 2022.
3. As the illness-narrative genre developed, a body of descriptive and critical scholarship emerges toward the close of the 20th century. Influential titles include Anne Hunsaker Hawkins's 1993 *Reconstructing Illness: Studies in Pathography*; Frank's 1995/2013 *The Wounded Storyteller*; and G. Thomas Couser's 1997 *Recovering Bodies: Illness, Disability, and Life*

*Writing*. Other notable scholarly titles include Arthur Kleinman's 1988 *The Illness Narratives: Suffering, Healing, and the Human Condition*; Ann Jurecic's 2012 *Illness as Narrative*; Kathryn Conway's 2013 *Beyond Words: Illness and the Limits of Expression*; and James Kyung-Jin Lee's 2022 *Pedagogies of Woundedness: Illness, Memoir, and the Ends of the Model Minority*. There are also many edited volumes including critical reflections upon the genre.

4. See Fleischman, 1998, 1003.
5. See Spencer, 2021a, 21–24.
6. Kathryn Montgomery Hunter discusses several examples of this trope, from Chekhov to William Carlos Williams to Richard Selzer (1983, p. 141), and in their study of physician writers, Aull and Lewis (2004) cite a number of such “physician-patients,” including Sherwin Nuland’s experience of his brother’s illness (Nuland, 1994) as well as Oliver Sacks’s *A Leg to Stand On* (1998) and *The Mind’s Eye* (2010).
7. See also Wear and Jones, 2010, p. 220.
8. See also: Brown and Garden, 2017, 504; Couser, 2004, 101–102; Pollock, 1996, 352; Spencer, 2021b.

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