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EDITORIAL

Body Language: Illness, Disability, and Life Writing

As much as we may like to evade or minimise them, illness and disability inescapably attend human embodiment; we are all vulnerable subjects. So it might seem natural and inevitable that the most universal, most democratic form of literature, autobiography, should address these common features of human experience. And yet self-life writing has reckoned with embodiment only relatively recently. In the Western tradition, we can date first-person life writing about illness and disability (which I have named *autosomatography*) from classic texts like John Donne's *Devotions upon Emergent Occasions, and Several Steps in My Sickness* (1624) and the essays of Michel de Montaigne. But such texts are rare—few and chronologically far between—until well after the birth of the clinic in the eighteenth century.

Granted, in the United States, the post-Civil War period saw a flurry of narratives of institutionalisation by former mental patients, a subgenre that adapted older American life writing genres, the captivity narrative and the slave narrative, to protest the injustice of the confinement of those deemed insane. But for the most part, autobiographical writing expressive of illness and disability remained quite uncommon until the second half of the twentieth century, when it flourished concurrently with successive civil rights movements. Women's liberation, with its signature manifesto *Our Bodies Ourselves*, supported the breast cancer narrative; the gay rights movement encouraged AIDS narrative in response to a deadly epidemic; and the disability rights movement stimulated a surge in narratives of various disabilities. Conversely, the narratives helped to advance the respective rights movements. Such writing, then, has been representative in two senses of the term: aesthetic (mimetic) and political (acting on behalf of). It has done, and continues to do, important cultural work.

Academics began to pay attention to these subgenres of *autosomatography* only around 1990. Although I was hardly aware of it at the time, I realise in retrospect that my interest in illness narrative had autobiographical stimuli. My mother survived breast cancer in her fifties only to succumb to ovarian cancer at the age of 64, in 1974, when I was a graduate student; a cousin my age died of breast cancer several years later. So I was intimately acquainted with stories I thought deserving of inscription and publication. For that and other reasons, as memoirs of illness and disability proliferated in the 1980s, I became convinced they were a significant new form of life writing, worthy of scholarly scrutiny.

Though not a scholar of British literature, nor a devotee of Virginia Woolf, when I stumbled on Woolf's marvellous essay 'On Being Ill', I was struck by its recognition of 'how tremendous [is] the spiritual change that [illness] brings, how astonishing when the lights of health go down, the undiscovered countries that are then disclosed' (9) and by its related claim that, 'considering how common illness is ... it becomes strange indeed that illness has not taken its place ... among the prime themes of literature' (9).

As Susannah Mintz's recent *Hurt and Pain: Literature and the Suffering Body* has demonstrated, Woolf was not entirely correct even about what she considered 'literature' (imaginative genres like poetry, drama, and fiction); as Mintz shows, canonical texts in those genres have been more amenable to the expression of illness and disability than recent critics (following Elaine Scarry) have claimed. Still, this was not as true of imaginative literature when Woolf made her claim, and, since her time, autobiographical writing has come to the fore as a medium in which to make sense of suffering, illness, and disability—and, more broadly, to express the experience of anomalous (but not necessarily painful) embodiment.

In 1990, I proposed and edited a special issue on illness, disability, and life writing for *a/b: Auto/Biography Studies*, a young journal open to new ideas (the issue 'Illness, Disability, and Life-Writing,' was published in 1991). In my own contribution, 'Autopathography: Women, Illness, and Lifewriting,' I wrote,

Though Woolf's remarks are concerned with imaginative literature, they are certainly relevant to life writing. Especially to the predicament of the female autobiographer, for [Woolf's] account of the suppression of illness in literature has as its subtext the domination of discourse by masculinist assumptions ... the Western privileging of mind over body, the tendency to deny the body's intervention in intellectual and spiritual life. (68)

In the 1990s, other critics mapped this new territory. Adapting the clinical term to refer to non-clinical narratives, Ann Hunsaker Hawkins's *Reconstructing Illness: Studies in Pathography* (1993) was the first monograph to pay sustained attention to this sort of life writing, beginning with Donne. Not long after her pioneering book appeared, Arthur Frank published the *Wounded Storyteller: Body, Illness, Ethics* (1995). A sociologist, Frank had survived a heart attack and cancer in early middle age; indeed, he had written an illness memoir of his own, *At the Will of the Body* (1991). His scholarly book, then, reflected the point of view of someone with personal experience of mortal illness, on the one hand, and, on the other, a social scientist's perspective on the roles assumed and assigned in medicalisation. He supplemented Hunsaker Hawkins's mythic approach with a tripartite division of illness narratives into 'restitution', 'quest', and 'chaos' stories—a distinction that has continued to be useful to students in the field.

In *Recovering Bodies: Illness, Disability and Life Writing* (1997), I examined life writing generated by four conditions—breast cancer, HIV/AIDS, paralysis, and deafness. At the time, there was still not much in the way of secondary source material; my method was to read all the book-length narratives of each condition that I could find, including some that were self-published. Given the context of the various rights movements, I was particularly interested in whether, and how, these narratives (mostly, but not all, first-person in point of view) responded to the dominant discourses (sexist, homophobic, and ableist) of the bodies in question. In addition, I exposed a more general rhetorical imperative that I termed 'the tyranny of the comic plot'—the strong preference in the literary marketplace for a positive 'narrative arc', i.e., a happy ending. Obviously, that demand militated against first-person narratives of HIV/AIDS, which was not survivable in the early days of the epidemic; it was similarly repressive of narratives of worst-case scenarios of cancer, chronic illness, and some impairments (what Frank labeled 'chaos narratives').

While this special issue addresses narratives of illness *and* disability, the two are not the same, and we should be wary of confusing or conflating them. Illness is properly addressed by the ‘medical model’, which interpellates subjects as ‘patients’, assigning them the ‘sick role’ and, ideally, bringing medical intervention to bear in a beneficial way. But disability often does not require or respond to biomedical treatment. Central to Disability Studies is a distinction pertinent here, between *impairment* (a dysfunction in the body, which may be amenable to cure, rehabilitation, or prosthetic modification) and *disability* (environmental features that exclude or impede those with impairments; these require altering the context—legal, social, and architectural—in which the impaired body functions). Hence the ‘social model’, which defines ‘disability’ as culturally and socially constructed.

And yet, though distinct in concept, illness and impairment often coexist in the same individuals. Indeed, in practice illness and impairment have a reciprocal relation: each may cause the other. Moreover, like disability, some illnesses—especially chronic or terminal ones—carry powerful stigmas. Illnesses, too, are susceptible to damaging social and cultural construction. For that and other reasons, recent work in Disability Studies questions the sharp distinction between illness and disability and indeed the utility of the social model. Having initially advanced the argument that disability is a harmful social construction, like race and gender, then, Disability Studies scholars are now reckoning with the limitations and flaws of that analogy. For instance, unlike other minority conditions manifest in the body, like race and gender, impairment involves disadvantages that are intrinsic, rather than extrinsic, and thus not amenable to discursive or institutional reform. Disability Studies is increasingly acknowledging that impairment may entail traumatic effects: chronic pain, progressive degeneration, and early death. Disability studies is coming around to a somewhat more favourable view of the biomedical model—at least, an acknowledgment that it is indispensable.

Given the ubiquity of illness and disability, it is notable that the distribution of narratives of anomalous physical conditions does not track their currency in the general population. A very few conditions still account for very large numbers of narratives: to the four I examined in *Recovering Bodies*, we could add depression (among mental illnesses), eating disorders, and, recently, autism spectrum disorders and dementia. Of course, parents continue to write narratives of severely disabled children, and most dementia narratives are written by carers, usually daughters or wives of male subjects. But with conditions that might seem to preclude first-person narration—like autism, other developmental disabilities, and dementia—the mere existence of autobiography and memoir itself challenges harmful preconceptions. Such texts are performative utterances; their composition enacts their message: there’s a person here, capable of self-understanding and self-expression.

At the same time, a large number of conditions have prompted small numbers of narratives. Over the years, my informal tally of these conditions has grown steadily longer; it now includes (in alphabetical order) amputation, amyotrophic lateral sclerosis (Lou Gehrig’s disease), anorexia, anxiety, asthma, bipolar illness, borderline personality disorder, cerebral palsy, chronic fatigue syndrome, chronic pain, Crohn’s disease, cystic fibrosis, deformity, diabetes, Down syndrome, epilepsy, insomnia, irritable bowel syndrome, locked-in syndrome, multiple sclerosis, Munchausen syndrome by proxy, obesity, obsessive-compulsive disorder, pancreatic cancer, Parkinson’s, prosopagnosia (face-blindness), prostate cancer, schizophrenia, stroke, stuttering, Tourette syndrome, and vitiligo. Some of

these conditions are very rare, or mysterious one-offs, like those impelling Susannah Calahan's *Brain on Fire: My Month of Madness* (an unusual autoimmune disorder that defied initial diagnosis) and *Head Case: My Brain and Other Wonders*, by Cole Cohen (a hole in her brain the size of a lemon, which accounted for her difficulty with spatial and temporal relationships). Other conditions, like large-breastedness or having undergone a lobotomy, don't qualify as illnesses or disabilities, but they involve unusual bodily configurations or experience. Collectively they constitute what I have dubbed 'some body [two words] memoirs' or 'odd body memoirs': they register the experience of living in, with, or as a particular kind of anomalous body. The appeal of such narratives is not so much to others with the condition in question (as with the narratives of more common, or more symbolically loaded, conditions) or even to those who may fear experiencing it themselves, but rather to a broader audience (which includes me) curious about what it's like to live in a body functionally or formally different from their own.

This list is not comprehensive; nor could it be: it seems that every time I browse a biography/memoir section in a large bookstore, I come across a new example. And if I think of a condition I am not aware of having been narrated, Google often proves me wrong. During the so-called memoir boom in North America, an unusual impairment or illness was considered a valid basis for a full-length memoir. Indeed, some popular examples, like Susanna Kaysen's *Girl, Interrupted*, have been adapted into film, and reached even wider audiences. Like Kaysen, the writers of these memoirs are often young women; like Cole Cohen and Lucy Grealy, author of *Autobiography of a Face*, some have earned MFA degrees from prestigious programs. Thus, professional writers have begun to flaunt bodily conditions they might once have hidden, or camouflaged in fiction. Illness and disability memoirs have achieved great popularity, critical esteem, and currency in contemporary media. Along with gay, queer, and transgendered people, ill and disabled people are coming out in life writing.

In the Internet age, the ease, decreased cost, and increasing respectability of self-publishing further facilitate such testimony. As a result, autosomatography proliferated dramatically around the turn of the millennium. Life writing about illness and disability has expanded—one might say exploded—into new modes and media as well. Beyond the realm of print stretches the vast expanse of cyberspace, which hosts blogs, online support groups, and other forms of self-representation. In addition, social media like Facebook and Twitter offer venues in which people with various medical conditions can issue running accounts of their welfare in real time, giving new simultaneity and immediacy to illness and disability narrative.

These phenomena should not be dismissed as facile or narcissistic. Whether a particular condition is heavily stigmatised or not, illness and disability can be isolating, and such isolation is inherently toxic. In this case, 'virtual' does not mean attenuated or artificial; virtual communities can provide vital resources, emotional support, encouragement, and stimulation in ways that actual communities sometimes fail to do. Indeed, in the case of rare conditions, face-to-face community may be simply unavailable. So the Internet provides a new kind of accessibility, especially important for those with mobility impairments. Social media can provide a sense of community that is itself therapeutic and healing.

In the United States, even mainstream media have participated in this dissemination of autosomatography. Susan Gubar, a feminist scholar best known as co-author (with Sandra

Gilbert) of *The Madwoman in the Attic*, has followed up her 2013 *Memoir of a Debulked Woman: Surviving Ovarian Cancer* with occasional blog posts in the *New York Times*. Similarly, diagnosed with terminal cancer at the end of a literary career spent writing about others' neurological impairments, Oliver Sacks narrated his dying in several essays published in the *Times*. More democratically, and more significantly, its online edition has hosted multiple sets of brief oral accounts of nearly 50 conditions under the rubric 'Patient Voices'. Readers can hear several ordinary people of different genders, races, and backgrounds discuss their experience of each condition. Clearly, autosomatography has come of age. I welcome this phenomenon, as it expands our sense of the range of bodily experiences humans may have. It begins to address, and redress, the Cartesian privileging of mind over body.

An additional aspect of illness narrative worthy of mention here is the advent and spread of Narrative Medicine—an approach to clinical care conceived and articulated by Dr. Rita Charon and institutionalised in the Program in Narrative Medicine at the College of Physicians and Surgeons at the Columbia University Medical Center (*Narrative Medicine*). This approach involves training medical professionals (not solely physicians) in narrative competence (both as readers and as writers) in order to make them more empathetic and attentive to the way in which patients experience and understand their conditions. Thus, it builds on the distinction between 'disease' and 'illness', where 'disease' refers to a disorder in the abstract, viewed through a biomedical lens, and 'illness' refers to a patient's particular experience of a disorder: the way it affects their life narrative, family dynamics, and so on. It approaches the patient's condition in a broad perspective comprehending its spiritual and emotional, as well as physical, dimensions. To borrow a coinage I only recently came across, we might call the goal 'empathography', rather than pathography (Lammer). The method imagines narrative not as the bald recapitulation of a series of events—ideally, from symptoms to examination, diagnosis, treatment, and recovery—but as the construction of meaning out of the distressing, disorienting, experience of bodily disorder. In Arthur Frank's terms, the former approach yields a 'restitution narrative', whose protagonist is the physician, rather than the patient; the latter approach, a 'quest narrative', whose protagonist is the patient as a *person*.

On the face of it, this approach is consistent with what I see as the deep subtext or, to put it differently, the 'work' of autosomatography—not the mere expression of experiences of illness and disability but the active reclaiming of them from medicalisation (this was the implication of the title of *Recovering Bodies*: that illness narrators can regain authority over their bodily lives). But as Charon has herself acknowledged, Narrative Medicine entails the risk of enhancing physicians' narrative competence at patients' expense: it may unintentionally augment biomedical authority over the illness narrative ('Listening'). Moreover, giving practitioners greater access to patients' private lives can invite, and may even encourage, ethical abuses, violations of the privacy of very vulnerable subjects. In any case, while it aspires to treat the whole person, Narrative Medicine is still and only a variant of the medical model; unlike the social model, it has no designs on the world.

Ultimately, illness and disability narrative are too important to be left to physicians; as much as possible, such narrative should be authored by those with the conditions in question. And perhaps more useful to clinicians than narratives they may co-construct as practitioners of Narrative Medicine would be the careful study of illness and disability narratives, beginning in medical school. I have long been a believer in, and advocate

for, the *clinical* value of *non-clinical* narratives of illness and disability. In this context I refer to autosomatography as ‘quality of life writing’—combining the sometimes problematic term ‘quality of life’ with the generic term ‘life writing’—because this body of work has great potential to demystify and destigmatise the conditions it recounts from the inside.

The essays in this issue sample, rather than survey, this rich, ever-expanding field. Because they discuss diverse kinds of materials from a variety of perspectives, they indicate numerous areas for future work. The first contribution, Ann Jurecic’s ‘The illness essay’, looks at once backward and forward. Glancing backward, its opening line informs us that ‘the essay was born out of suffering, injury, and recovery’. She is referring here to the inventor of the personal essay, Michel de Montaigne. I regard Montaigne’s ‘On a Monster-Child’ as marking the moment in Western culture when it became possible to view a highly anomalous body not as a ‘wonder’—an omen—but rather as a mere freak of nature, so I am glad to lead off the issue with this acknowledgment of him. Jurecic’s essay is forward-looking as well, however, in its focus on an emerging genre, the lyrical essay, which can address illness and disability in ways that sidestep the need for a narrative arc. As the term ‘lyrical’ suggests, her exemplary texts—Leslie Jamison’s *The Empathy Exams*, Eula Biss’s *On Immunity: An Inoculation*, and Rebecca Solnit’s *The Faraway Nearby*—draw on the resources of poetry to express aspects of embodiment in original and challenging ways.

Given the importance of Virginia Woolf’s essay ‘On Being Ill’, it seems apropos that the issue should include Janine Utell’s ‘View from the sickroom: Virginia Woolf, Dorothy Wordsworth, and writing women’s lives of illness’. In it, Utell explores Woolf’s literary connections with Dorothy Wordsworth, and also Elizabeth Barrett Browning, as expressed in various genres, including diaries and biography. Her focus is on how women may use writing to create ‘a transgressive space’ outside ‘normal’ life in which to negotiate complex relations with their minds and bodies.

The following article, Susannah Mintz’s ‘Mindful skin: disability and the ethics of touch in life ‘riting’ represents a foray into relatively unfamiliar territory (for me, at least). It focuses on the body in a very particular way—on a very fundamental, but too often ignored, sense (‘the body’s most primitive’ one), that of touch—but it is also attentive to the mind. The point is of course that the body and mind are not merely in touch with each other, so to speak, but inextricable elements of one entity, aspects of a single existential and ontological being. Mintz brings together seemingly disparate phenomena—Buddhist mindfulness, disability activism, and the ethics of care—in an innovative and fruitful way. She concludes with a discussion of Mark O’Brien’s memoir *How I Became a Human Being* (the basis for the motion picture *The Sessions*) and Sharon Cameron’s *Beautiful Work: A Meditation on Pain*.

One of the liveliest new venues for autosomatography has been graphic narrative, so I am grateful for Krista Quesenberry’s and Susan Merrill Squier’s ‘Life writing and graphic narratives’. They trace the origins of graphic memoir and speculate about its potential for the representation of illness and disability. (One significant aspect of autosomatography in graphic form is that it renders the affected body visible to readers in a way that print does not). Their collaborative contribution is innovative in form, as well: it comprises an exchange of emails between the two as they develop ideas and insights about the new

genre. Graphic narrative is already being employed in medical education, and it bids to become much more common, so their analysis is particularly timely.

As my former colleague James Berger has pointed out, Disability Studies has been slow to reckon with the traumatic nature of disability—for family and friends as well as for the disabled themselves (“Trauma”). Similarly, Trauma Studies has largely ignored disability as an arena of trauma. Margaret Torrell’s contribution, ‘Interactions: disability, trauma, and the autobiography’, helps to address and repair these oversights. After a discussion of the methodology of the two fields, she uses Kenny Fries’s memoir *Body, Remember* to demonstrate how the two approaches may complement each other.

Earlier, I touched upon the critical role that illness and disability narratives can play in medical education, beyond their appeal to lay readers. And I noted that Narrative Medicine, though collaborative, tends to situate authorship and authority in the physician. Richard Freadman’s and Paula Bain’s ‘Life writing and dementia care: a project to assist those “with dementia” to tell their stories’ demonstrates the possibility, and profit, of having patients author their own stories, albeit with some coaching and assistance. There are ethical dangers here, of course, but it seems clear that under the best of conditions, patients—even (or especially) those who may be losing their self-narrative competence—can benefit in multiple ways from engaging in this process. The Freadman-Bain project of leading a therapeutic writing group for dementia patients illustrates the utility of self-narrative in addressing deficits in memory and cognition. These narratives serve their authors, first, by activating and exercising their memories in the process of composition; later, as records the authors can consult for reference and value as personal creations; and still later, as memorials available to posterity.

One of the features of *Life Writing* that I have always valued and enjoyed is its *Reflection* section. This issue contains two contributions under this rubric.

Hugh Kiernan’s “‘Ah, but I was so much older then, I’m younger than that now’: cancer and a virtual relationship’ is in itself a kind of double feature. It arises from Kiernan’s virtual acquaintance with another cancer patient, forged in an on-line writing forum. Kiernan has published his own narrative of living with multiple myeloma. He keeps his own illness experience in the background here, though, to showcase and respond to the poetry of his much younger female friend, who has a very different kind of cancer. In addition to introducing her voice, and enriching the issue’s range by including autosomatography in poetic form, this piece testifies to the value of the Internet as a site for vital connection among those with illnesses and disabilities.


The issue concludes with Joanne Limburg’s “‘But that’s just what you can’t do’: personal reflections on the construction and management of identity following a late diagnosis of Asperger syndrome’. Sometimes forgotten in the study of illness and disability is the subject’s obligation to enact a certain role: to play disabled, to assume the sick role, to *present* as ill or disabled. In this case the irony is that Limburg, who was diagnosed with Asperger’s as an adult, needs to perform her disability in order to ensure that she qualifies for legal benefits and accommodation. Disability rights laws are invaluable enactments of the social model, but their application may impose peculiar burdens on those they purport to benefit. In this case, writing back (and humorously) may be the best revenge.

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