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APA referencing

Couser, G.T. (2018). Illness, disability, and ethical life writing. *Comparative Literature and Culture*, 20 (5), 1–7. <https://docs.lib.purdue.edu/clcweb/vol20/iss5/2/>


Family history referencing (footnote)

G. Thomas Couser, 'Illness, disability and ethical life writing', *Comparative Literature and Culture*, vol. 20, no. 5, 2018, pp. 1–7, <https://docs.lib.purdue.edu/clcweb/vol20/iss5/2/>

Illness, Disability, and Ethical Life Writing

G Thomas Couser

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Recommended Citation

Couser, G Thomas. "Illness, Disability, and Ethical Life Writing." *CLCWeb: Comparative Literature and Culture* 20.5 (2018): <<https://doi.org/10.7771/1481-4374.3482>>

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Volume 20 Issue 5 (December 2018) Article 2**G. Thomas Couser,****"Illness, Disability, and Ethical Life Writing"**<http://docs.lib.purdue.edu/clcweb/vol20/iss5/2>

Contents of *CLCWeb: Comparative Literature and Culture* 20.5 (2018)**Special Issue: *Voices of Life, Illness and Disabilities in Life Writing and Medical Narratives*.****Ed. I-Chun Wang, Jonathan Locke Hart, Cindy Chopoidaló, and David Porter**<<http://docs.lib.purdue.edu/clcweb/vol20/iss5/2>>

Abstract: In his article "Illness, Disability, and Ethical Life Writing," G. Thomas Couser discusses illness and disability as related to ethical Life Writing. Since the issues came to his attention in the early 1990s, narratives of illness and disability have continued to proliferate in the US. And today, even as psychiatry moves away from narrative therapy toward drug therapy, narrative competence is being emphasized in the treatment of non-mental illness. Whether inside or outside the clinic, narratives of illness and disability can be in and of themselves restorative, if not healing. And yet, the production of such narratives is not without ethical pitfalls. Professional ethics do not necessarily prevent violation of privacy or other harms.

G. Thomas COUSER

Illness, Disability, and Ethical Life Writing

Since they came to my attention in the early 1990s, narratives of illness and disability have continued to proliferate in the US. And today, even as psychiatry moves away from narrative therapy toward drug therapy, narrative competence is being emphasized in the treatment of non-mental illness—at least by some (notably Rita Charon, who has advocated for what she calls "narrative medicine").

This is all to the good. In her introduction to *Depression and Narrative: Telling the Dark*, Hilary Clark said it well: "We should listen to personal narratives of illness and disability—really attending to them on their own merits, as opposed to using them in order to come to diagnoses and impose regimes of treatment—because such narratives give voice to the ill, the traumatized, and the disabled, those trying to make sense of catastrophic interruptions or shifts in their lives and help them navigate the bewildering, impersonal context of medical diagnosis and treatment." (3)

Of course, such narratives are hardly limited to the clinic. Indeed, I have argued that in the US, the memoir boom coincided with, and to some extent was driven by, the rise of what I have dubbed the "some body memoir." Not the somebody memoir—the story of a celebrity. Rather, the story of a hitherto unknown person—a nobody—who has an anomalous somatic condition. Here are some conditions that have been the subjects of memoirs in the twenty years or so: amputation, amyotrophic lateral sclerosis (also known as Lou Gehrig's disease), anorexia, anxiety, autism spectrum disorders, bipolar illness, borderline personality disorder, bulimia, cerebral palsy, chronic fatigue syndrome, chronic pain, cystic fibrosis, deformity, depression, diabetes, epilepsy, insomnia, locked-in syndrome, Lyme disease, multiple sclerosis, Munchausen syndrome by proxy, obesity, obsessive-compulsive disorder, Parkinson's disease, prosopagnosia (face-blindness), schizophrenia, stuttering, stroke, Tourette syndrome, and vitiligo. Indeed, one might say that illness narrative has been something of an American literary epidemic of late. Whether inside or outside the clinic, such narratives can be in and of themselves restorative, if not healing.

Nevertheless, as I argued in *Vulnerable Subjects: Ethics and Life Writing*, the representation of illness and disability in memoir and autobiography is not without dangers. My subtitle, "Ethics and Life Writing," implies a very broad scope, but my primary concern was with subjects vulnerable to exploitation or misrepresentation by virtue of their being ill or disabled and sometimes, as a result, not able to represent themselves. My method was to adapt to the ethics of life writing a version of biomedical ethics known as Principlism, as set forth in a classic text, *Principles of Biomedical Ethics*, by Tom Beauchamp and James Childress. I was concerned primarily with texts whose subjects are rendered vulnerable by their relation to those who write about them. One category of such individuals is disabled children who are the subjects of parental narratives. Another category is located at the other end of life: aged and demented parents, whose predicament is the focus of a fast-growing niche narrative, the Alzheimer's memoir, typically written by a child who has served as a care-giver. Here we see a common linkage among healthcare, authorship, and authority; the writer claims authority on the basis of care-giving. This is an obvious and legitimate basis of authority, but it is not without complications.

According to my ethical schema, just as physicians are charged with not harming their patients, life writers should be concerned with not harming subjects with whom they are embedded in intimate and trust-based relationships. And just as physicians are obliged to honor their patients' autonomy, life writers should honor their subjects' autonomy, involving them in the process to the greatest extent possible. Finally, just as physicians are urged to be open with patients, so life writers should be transparent about their methods, processes, and personal benefits.

In *Vulnerable Subjects* I spent a good deal of space surveying the oeuvre of Oliver Sacks and offering a mild critique of his writing, which, though, empathetic is rarely informed by the insights of disability studies. I also examined what I call "death-writing"—euthanasia narratives, which typically justify the act on the grounds of poor quality of life. And I branched out from such obvious scenarios to the way anyone's life may be written by their DNA, which can reveal potentially harmful and costly genetic anomalies. To date, most of us are not compelled to submit our DNA to anyone, but it can be easily accessed without our permission or even our knowledge. In a sense, then, we are all vulnerable subjects. Keeping that in mind should encourage us to respect the autonomy of those who are rendered especially so by dint of the anomalous condition of their bodies and minds.

What, then, are some dangers inherent in writing about vulnerable individuals? What may compromise this enterprise? When and how might it have unintended and unfortunate consequences?

Consider the following history of a case study. After I spoke at an American university on an unrelated topic a few years ago, a graduate student I'll call Julia approached me with her story. At the age of

seven, Julia was operated on for a significant physical anomaly that required ongoing medical attention. To help her cope with this regimen, she was sent to a therapist. Nearly two decades later, learning that the therapist had been appointed to a prestigious academic post, Julia looked her up online, out of curiosity. The therapist's résumé listed an article Julia guessed was about her; reading it confirmed her suspicion.

She found the experience deeply unsettling. With her permission, I cited her story in an op-ed in *Virtual Mentor*, the online ethics journal of the American Medical Association; I called my essay "The Case History and Deferred Pain." (The term "deferred pain" obviously puns on referred pain, the medical term for pain that is felt somewhere other than its source. Referred pain is displaced in space; deferred pain—such as the belated pain felt by Julia—is displaced in time.)

This anecdote illustrates, for starters, how the internet has shrunk our world. We all have less privacy than ever before, and it is ever easier to trace others and references to ourselves. Scenarios such as Julia's, however, do not require the internet: in 2001 a psychotherapy patient queried the *New York Times* ethics columnist after discovering what he believed to be his case narrative while randomly browsing in a bookstore.

These stories reveal that even when authors of case studies may *think* they have concealed the identity of their patients, there is no guarantee that patients will not recognize themselves should they happen upon their own narratives. And such recognition is very likely to cause them discomfort.

These therapists presumably thought they had done everything required by professional ethics. Perhaps they had. Julia was too young to grant consent; rather than seeking it from her parents as proxies, the therapist concealed her identity behind a pseudonym. Moreover, Julia's youth may have led her therapist to discount the likelihood of her reading the article. But eventually she did, and she readily recognized it as her case. And she felt somehow violated, or betrayed.

Ironically, the adoption of narrative medicine may increase the likelihood of scenarios like this. With this approach—which, according to Rita Charon, elicits "accounts of self... that include emotional, familial, aspirational, creative aspects of the self"—a physician's relation to her patients approaches that of a psychotherapist ("Listening"). As I said earlier, this may serve the patients' interests; such is the aim (and claim) of narrative medicine. But greater knowledge of patients' lives also facilitates the writing of case studies that may result in self-recognition and feelings of violation of privacy. Indeed, at the 2011 MLA convention, Rita herself noted the danger inherent in narrative medicine. Her title—"Listening, Telling, Suffering, and Carrying On: Reflexive Practice or Health Imperialism?"—indicates the prospect that, rather than empowering patients, this approach may extend clinicians' power over them. It may thus increase the risk of what I call "deferred iatrogenic pain"—suffering inflicted on patients not by their treatment but by the *narratives* of that treatment.

The point is that ethical guidelines do not guarantee that case histories will not cause pain to their subjects. Such pain may not rise to the level of clinical "harm," and thus the clinicians may not have violated the precept to do no harm. But in Julia's case, the pain was far from negligible, despite being long delayed. More to the point, it may have been avoidable.

Or maybe not: it may not always be possible to conceal patients' identities from them. The rarer the case, the more publishable it is. And the very details that warrant its narration may enable patients to recognize themselves. In any event, among all the potential readers of case studies, patients are uniquely equipped to know the identifying details and, of course, who provided treatment. They may resent the presumption of authorship on the part of care-givers.

Even if their rights have not been violated, the question is whether their discomfort is outweighed by the benefits of the narrative. The question then becomes, *cui bono?* Who benefits? Who profits? Presumably, the goal of writing case histories is to advance the understanding of particular conditions and improve treatment. In principle, then, the case history serves the welfare of all—public health. At the same time, there are undeniable benefits to the author in committing a case to print. Doing so can build a reputation and advance a career—and lead to monetary gain. Consider Oliver Sacks, the world's most famous neurologist, whose fame and fortune are based not on his clinical practice or contributions to neurology but on his nonclinical case studies of unusual syndromes. So the writing of case studies may entail an inherent conflict of interest: authors stand to gain from them in a way that is not true for their subjects. This could affect their judgment of the medical benefits of such projects.

I cannot speak for Julia; indeed, she herself is not sure just why she was so troubled by reading her case. But my sense is that a patient's discomfort may be a function of the intrinsic disparity between the patient's and the clinician's relations to a case. The patient comes to the clinician in hope of help—of care, if not of cure. To the professional, however, the patient represents an instance of something beyond herself; with specialists, the condition is often one in which the professional has an intellectual

interest, or even a research program. The hurt caused by a patient's self-recognition may arise from the feeling that one has been reduced to one's condition and thereby objectified.

What disappoints and offends a patient who reads her own case narrative, then, may be the discovery that she is not just a person, or even a patient, but also a case--indeed a case *of*--to her therapist or physician. The psychotherapist Ruthellen Josselson has acknowledged this. Confronted with clients' negative reactions to their case histories, she came to this realization: "I [had], in a sense, been talking about them behind their backs and doing so publicly. Where in [therapy] I had been responsive to them, now I [was] using their lives in the service of something else, for my own purposes, to show something to others. I am guilty about being an intruder and then, to some extent, a betrayer" ("On Writing," 4).

Thus, the patient who reads her own case may make the uncomfortable discovery that, in the therapeutic relationship, her wellbeing was not an end in itself--or at least not the only end: she has also been a means to an end. Whether she values that end may depend on what she takes it to be. If she sees her case as being used to advance knowledge of her condition, she may decide her discomfort is justified. If she sees the end as more careerist, she may not.

Those who write about illness and disability, then, should err on the side of caution. It may not be enough to take the precaution of concealing a patient's identity--or obtaining consent. The patient who gives consent may have no idea what it will be like to come upon her story in alien discourse. It may be advisable to assume that one's patient will in fact read the narrative of her case and recognize it as her own. And to write accordingly, if one writes at all. And not to write, if one imagines it will cause undue discomfort.

As it happens, that story has an instructive kicker, or afterlife. Not long ago, Julia emailed me to say that she now felt ready to write about her situation. She asked if she could see what I had written. I thought I had sent her my op-ed when it was published. Apparently I had not. So I sent it to her, and she replied (in part) as follows: "I think that [your] article captures that invalidation of my feelings rather perfectly, but not in a way that is self-aware. In other words, [your] article unconsciously replicates the same single focus on an external goal, and lack of attention to internal processes and family dynamics, that I felt during the therapeutic process" (personal communication).

I'm not entirely sure what she means about "internal processes and family dynamics," since, unlike her therapist, I was not privy to those nor to any of the details of her case. In fact, I don't even know what her original condition was. But in writing my piece, I was uncomfortably aware that I, too, was treating it as a kind of case and putting it to my purposes. I saw no way around that, and I don't regret what I did with it. But I understand how Julia may feel I somehow reenacted her therapist's appropriation of her experience. My point is that writers cannot always foresee how far their words will travel and how they may return to haunt them.

In writing *Vulnerable Subjects*, it occurred to me that the various principles of biomedical ethics might be boiled down to one precept, known in the Judeo-Christian tradition as the Golden Rule: do unto others as you would have others do unto you. That seems unobjectionable. But it's not, because it encourages a very dangerous ethical practice: assuming one knows what the other wants. Not only do individuals vary in what they want, but desires may be inflected by gender, race, ethnicity and other cultural attributes. This is one reason that diversity in the medical profession is so imperative.

But it may be that the bias hardest to overcome in medicine--and in medical discourse--is that against illness itself. But how is this a bias? Isn't the mission of medicine to heal the sick? Shouldn't physicians be against illness?

In a sense, yes, of course. This preference for health--to name it more neutrally--is inherent in medical practice and rightly so. At the same time, it is increasingly obvious, to those paying attention, that medicine operates inside, rather than outside, of cultural contexts. Most of the time, medicine's constructs work well enough. But medicine often encodes, and thus reinforces, common prejudices against certain kinds of bodies.

Good evidence of this, if we needed it, appeared in a recent TED talk by Dr. Peter Attia, who, according to a *New York Times* story, "admitted to something he believes many doctors may in fact be guilty of. That compassion for overweight and obese patients often is not quite as deep as it is for those who are sick for other reasons -- the 'unlucky' ones, for instance, who develop cancer or another disease through no apparent fault of their own" (O'Connor). Many viewers were moved by his apology to a diabetic patient he admitted blaming for her condition. I would be more impressed by his apology had it not been prompted by Dr. Attia's own diagnosis with diabetes despite what he considered his very healthy life style. In any case, Dr. Attia is not alone. The *New York Times* recently ran an article with the title, "Why Do Obese Patients Get Worse Care? Many Doctors Don't See Beyond the Fat."

The larger point here has been a theme of my work beginning with *Recovering Bodies: Illness, Disability, and Life Writing*: certain somatic conditions come with stigmatizing narratives. In my lifetime,

the most obvious example of this is, of course, HIV/AIDS. Initially, HIV/AIDS was considered a death sentence, and the cultural narrative implied that many patients deserved their sickness and their death. Hence the distinction between innocent and not-so-innocent victims, depending on how the virus was acquired—whether by intravenous drug use or gay sex, on the one hand, or by transfusion or birth, on the other. This stigma has been greatly diminished—fortunately, but not fortuitously, that is not by chance. One factor was drug therapies that have made HIV/AIDS a survivable chronic condition. This changes the narrative and reduces fear and stigma. But those advances were impelled in part by gay activists: such is the interplay among culture, politics, and science. My point may be obvious, but let me restate it: many illness and disability narratives are pre-inscribed by culture. Attentive writers—and readers—of life writing need to be aware, and wary, of these preexisting scripts, which have great power and inertia.

Hitherto, I have been using the terms illness and disability in tandem. Now, having raised the question of a medical preference for health, I want to distinguish disability from illness. Admittedly, in practice the two often overlap; they often coexist in the same bodies. Indeed, illness and disability have reciprocal relations: each may cause the other. Moreover, for legal purposes, under the Americans with Disabilities Act, many physical illnesses—like HIV/AIDS, cancer, and diabetes—and mental illnesses—like schizophrenia and bipolar syndrome—count as disabilities. Thus, while illness and disability are conceptually distinct, the ill and the disabled are not distinct populations, and the line between disability and illness is not always clear.

But while it is very difficult to draw a sharp line between them—or even to articulate the difference—there is a distinction, and it matters. It matters in part because the all-too-common conflation of disability with illness necessarily engages the medical paradigm (with its preference for health and wholeness). This paradigm hails, or interpellates, disabled people as sick and defective; it constructs their conditions as requiring medical intervention, which is not always helpful or desired. This conflation tends to pathologize disability, willy-nilly. It may project a desire for cure where it does not exist.

A related danger of conflating disability with illness lies in undervaluing the lives of disabled people. Numerous studies have established that people with significant disabilities rate their own quality of life nearly as high as that of nondisabled people. Many disabled people are surprisingly well adjusted to their conditions, especially if their impairments are congenital or acquired early in life. In contrast, nondisabled people, especially those who are medical professionals, typically estimate the quality of life of disabled people as quite poor. Here, I think, we can begin to see the danger of the medical bias in favor of health. Disabled people do not share, cannot understand, and are justifiably offended by the attitude of nondisabled people that their lives may be of poor quality—or even not worth living. So there is always a danger in writing about someone's disability that the writer will project onto a subject his or her own imagined response to being in that condition. The Golden Rule falls short.

A few years ago, the *New York Times Magazine* ran a cover article about Brooke Hopkins, an English professor at the University of Utah, who became a high quadriplegic as a result of a terrible bicycle accident (Marantz). The story's hook was that he was married to a prominent bioethicist, Margaret Pabst Battin, who had long been an advocate of assisted suicide: now her beloved husband was an apparent candidate for that final solution. I always dread reading these stories, as they generally conclude that, for the severely disabled, suicide is justified. This article reserved judgment; at the time of publication, Hopkins was still alive and apparently holding his own. (He has since died.) I was heartened, however, by his testimony that he loved his life—mostly (not every day)—and that "You never know what you can get used to." Indeed, you don't. You can't, until you have to.

Developments in the relatively new field of psychology called hedonics—the study of what pleases us—lend the authority of behavioral science to disabled people's reports of their quality of life (Amundson). Medical professionals should respect these reports—whether they agree with them or not—and to treat disabled people accordingly. Life writers—parents of disabled children, siblings of disabled persons, children of disabled parents—should heed them as well. In fact, I have coined the term "quality-of-life writing" for narratives of illness and disability to recognize their role in affirming quality of life where it may not be apparent to others.

My argument may seem rather negative; it certainly has been primarily cautionary, a series of caveats.

- Life writing can cause harm when consumed by the subject, even years in the future.
- Life writing can violate the privacy of its subject.
- Life writing can appropriate a subject's story for ends that the subject may not value.
- Life writing can project onto an ill or disabled subjects the emotions its authors think they would feel in their situation; such "identification" can itself be invalid and harmful.
- It is problematic to conflate illness and disability.

But let me close by coming at these issues from a very different angle, drawn from my own life and my own life writing. I was initially drawn into the field of Disability Studies by the proliferation of memoirs by and about people with anomalous bodies. I was not consciously impelled by any personal experience. Had you asked me twenty years ago, I would have said that neither I nor any member of my immediate family was disabled. But I see now that in fact my family was riddled with disability; I just hadn't thought of it as such. I'll spare you the details except for this: when I was in my late twenties, and he was in his late sixties, my father died of depression—by way of self-medication with alcohol.

Over the last decade, I have worked on a memoir of him—an entirely unanticipated culmination of years of working in the fields of life writing studies and disability studies. The memoir was provoked mainly by personal documents I found in my father's closet that revealed dimensions of his premarital life of which I knew very little, and which I found fascinating. I thought that his life before he married and had children was worthy of narration.

To complete the narrative, however, I felt I needed to tell the sad story of his final years. To that end, I requested his medical records from McLean Hospital in Belmont, Massachusetts, where he had been treated for depression, without apparent benefit. (That is the same prestigious institution where Susannah Kaysen spent 18 months a few years before my father; a sojourn that was the subject of her memoir *Girl, Interrupted*.) After filing all the requisite forms, I received a batch of documents more than an inch thick. Much of this consisted of graphs of his electroshock therapy. These pages were of course totally inscrutable, entirely useless to me. The written observations by healthcare workers—social workers, nurses, and physicians—also supplied little in the way of insight into his psyche.

For over four months in his mid-sixties my father received the very best inpatient care that medicine could provide and that money could buy at the time. Alas, there was no discernible improvement in his condition, and a year after his discharge he died. What I learned from perusing his records several times is something I should perhaps have known all along: the answer as to why my bright, accomplished, vigorous father should succumb to a devastating depression in his early sixties was not to be found in his medical records. Indeed, the psychiatrist who referred him to McLean admitted he found no precipitating events. Nor did those who treated him while he was there.

I like to think that, using the documents and records available to me, and my personal knowledge of him, I have come to a better understanding of his late-life depression than his careers did. I did this by paying careful and sustained attention to the whole of his life course, with the benefit of documents not available to his physicians.

Obviously, in doing so, I have been writing about a vulnerable subject. In so doing, I experienced ethical questions firsthand, from the perspective of the memoirist, not the life writing scholar. The end of my father's life involved some very messy scenes. There is no question that he would not have wanted some stories told. So I was somewhat perplexed about what was fair to include. There's a vivid scene in Philip Roth's *Patrimony* in which he describes—in violation of a promise to his father—cleaning up after his father had an episode of explosive diarrhea—shit everywhere. I sympathize with Roth's predicament: I've witnessed some awful messes myself, and I feel they are part of my story, too; mine to share. So I sometimes question my own pronouncements about the ethics of life writing. Or at least, I recognize how easy it was to render them from a critic's, rather than a writer's, perspective. The pen is in my other hand, now.

Toward the end of the multi-year process of researching and composing this narrative—a process that was painful but also deeply gratifying and therapeutic for me—I had a brainstorm. For a number of reasons, it occurred to me that it might be appropriate to cast my memoir in the form of a long *letter* to my father—to address it to him explicitly, referring to him in the second, rather than the third, person. I rewrote the entire manuscript accordingly. On the advice of some readers, I abandoned this approach. But rewriting the memoir in the second person was an edifying experience. For one thing, it gave me the sensation of being in a new and direct relationship with my dear dead dad. It thus endowed the memoir with a degree of intimacy earlier drafts lacked.

The second-person address also helped me gauge what I was doing insofar as it made me acknowledge, to my father's face, as it were, just what I was revealing about him to anonymous readers. It feels different to address your narrative to your vulnerable subject. It's a good reality check, which may cause one to change one's tone or even one's content. I recommend this strategy to anyone writing about a vulnerable subject. Don't try to put yourself in their position, which is impossible; rather, try telling their story to them. It may help you to question your own authority, and thus to earn it.

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