



Received: 23 April 2017
Accepted: 14 June 2017
First Published: 19 June 2017

*Corresponding author: Arthur W. Frank, Professor Emeritus, University of Calgary, 5904-84 Street N.W., Calgary, Alberta, Canada T3B 4X5; VID Specialized University, Oslo, Norway
E-mail: arthurwfrank@gmail.com

Reviewing editor:
Susan Cox, University of British Columbia, Canada

Additional information is available at the end of the article

LITERATURE, LINGUISTICS & CRITICISM | CRITICAL ESSAY

An illness of one's own: Memoir as art form and research as witness

Arthur W. Frank^{1,2*}

Abstract: The author reviews his own experiences of writing an illness memoir, asking what makes such storytelling possible. How telling stories about suffering can precipitate healing is then considered. Finally, the argument pivots to health care research, asking what sort of research would be consistent with the ideas about illness that have been expressed.

Subjects: Cultural Studies; Literature; Health & Society

Keywords: illness narrative; healing; suffering; storytelling; healthcare research

1. Introduction

My beginning is my experience of turning my own illnesses into a story that I was able to tell and that others would listen to, two conditions that are essential for storytelling and do not go without saying. Those reflections lead to considerations of what people need to tell their stories, and more specifically, how expressing what has happened shapes what we call *experience* in the direction of healing. I then consider health care research in light of what has been said about storytelling and healing. I return to a question that has often concerned me (for example, Frank, 2001, 2005, 2010): how can research adequately represent experience?

2. Time in dark woods

The literary author whom I have read most consistently throughout my life has been Dante. Every time I begin another journey through the *Commedia*, I'm hooked by the first line, probably the most famous among all the great lines in this great poem. "In the middle of the journey of our lives, I found myself in a dark wood." This wood is a place of terrors. The poet is trapped on a hillside, both ascent and decent blocked by threatening animals. Then out of nowhere Virgil arrives and promises Dante a way out, but that requires undertaking a journey that begins with decent so that later there can be ascent. Dante will have to travel through Hell and Purgatory in order to reach Heaven. I do not believe in hell, or purgatory, or heaven as places. I believe absolutely in shape of the journey Dante takes us on.

ABOUT THE AUTHOR

Arthur Frank lectures internationally on illness, storytelling, and therapeutic approaches to suffering. In Calgary, he collaborates on developing "Hamlet in the Hospital," an arts-based support project for ill people. His current and forthcoming articles appear in journals including *The Hastings Center Report*, *Perspectives in Biology and Medicine*, *Literature and Medicine*, and the *Journal of Medical Humanities*. He was the 2016 winner of the Canadian Bioethics Society's lifetime achievement award.

PUBLIC INTEREST STATEMENT

Living with illness can be oppressive. But telling stories about an oppressed life can be liberating. This article takes readers into the dark place of deep illness, and then it shows how storytelling can lead to healing. The final section asks how health care research can better amplify the voices and knowledges of the ill.

A recent English translation of Dante is by the English critic and poet Clive James (Dante, 2013). For our purposes, what matters is that James undertook his translation of Dante after years of study, but on the immediate occasion of being diagnosed with the cancer that has, remarkably, not yet killed him. James exemplifies writing as a mode of survivorship (see also James, 2015). I see no basis for claiming that writing has prolonged James's life. My claim is that writing enriches the lives of people living with what I called, many years ago, *deep illness* (Frank, 1998). When I coined that phrase, I was trying to get at conditions like James's: illnesses that are both critical and chronic. Deep illness is not only a physical condition by a psycho-spiritual one. It requires finding a way to live in the perpetual shadow of illness, or in the phrasing I prefer, living with illness as a companion.

In Philip Pullman's contemporary masterpiece *His Dark Materials* there is a chapter titled "Lyra and Her Death" (Pullman, 2000). It's not a spoiler alert to tell you that the hero does not die in that chapter. Rather, she *meets* her death in the sense of being introduced to a being that has always been with her, but has been an unseen companion, never perceived as being there. Her death now becomes a self-conscious awareness; many but not all people reach that moment. Deep illness effects that recognition that death has always been our companion. It takes a while to learn to live with deep illness. It requires telling the story of your life differently.

I found myself in my own dark wood in 1985–1986, when in contiguous succession I had a heart attack and then cancer. A year after my own cancer treatments ended, my mother-in-law's final remission from breast cancer came to an end, so my wife and I were back in the cancer center, sometimes the same rooms, this time in support of her. While I was going through all this, I had neither the time nor the energy to write more than the odd note to myself. It's difficult to convey exactly how busy cancer treatment is. By the end I had a lot of memories, but I did not yet have a coherent sense of experience. Finding myself in this new condition of remission—the Purgatorial stage of illness—I had a problem that still receives too little recognition in writing about recovery from critical illness: Who was I? For what had seemed like an eternity I had been someone with cancer, a patient. Now I was in remission from cancer, still a patient but not on a daily basis. What did I call myself, and how was I to know myself?

Over the years, I have heard many poignant expressions of people's sense of alienation once they were in remission from cancer. These stories described how supportive their family and friends were during the treatment phase of the disease, but then that support ended once treatment was over. In Australia, in the late 1990s, I worked with a young woman who was recently in remission. She talked about how uncomfortable her family was with her continuing involvement in cancer advocacy and support groups. They wanted cancer just to be over, full stop. "But," she once said in a public lecture, "I had a lot more to say." Fortunately, she found venues to say it.

"I had a lot more to say" could be the title of this article. I myself had a lot more to say in 1989, after my remission had settled into a state of familiar disruptions caused by false-positives on follow-up examinations—those follow-ups did more than anything to keep me in a condition of deep illness. So, having a lot more to say, I did what I do, which is to write. Had I been a painter or sculptor, a musician, or a dramatist, I would have said what I had to say in that idiom. How one expresses oneself makes real differences, but people say what they have to in whichever medium they have resources. I was lucky in having considerable resources. Unlike most ill people, I had already written a good deal about illness, going back to my doctoral dissertation, 15 years earlier, about memoirs of spousal and parental deaths.

Despite this background, it took me some time to find the right authorial voice for what became *At the Will of the Body*, my memoir published in 1991 and still in print in its second edition (Frank, 1991/2002). In bringing that book into tangible, physical form, I was creating for myself the *companion* that I had sought throughout my illness. Just after I was told I had had a heart attack, I went looking for a book that could help me orient myself in this new space of medical demands and altered self-perception. On the account of the philosopher Alasdair MacIntyre, we humans need

stories “in order to be able to understand how others respond to us and how our responses to them are apt to be construed” (1984, p. 216). Part of what makes an illness *deep* is that it alters both how others respond to us and how our responses to them are likely to be understood.

I was 39 when my heart problems began and 40 when I was diagnosed with cancer. In the middle of life’s journey, I needed a Virgil to guide me, and the few companion memoirs I might have found—especially Audre Lorde’s *Cancer Journals* (1980) and Stewart Alsop’s *Stay of Execution* (1973)—were, in those days before online book ordering, unknown or unavailable to me, as comparatively well connected to books as I was. I remember my excitement when I finally obtained copies of both books, some years later. The metaphor of reading *hungrily* is appropriate.

But even if I had found good companions much sooner, eventually everyone has to say for themselves what they have to say. My usage here of “everyone” betrays a bias. Not everyone has more to say. The novelist J.M. Coetzee recently wrote a non-fiction book called *The Good Story* (Coetzee & Kurtz, 2015), and for me that most interesting part is when he questions the Oedipus story and how it has been construed in Western culture. The dominant belief perpetrated by the *Oedipus* via Freud is that crimes must be aired; in Thebes, the repressed murder and unwitting incest bring plague, and only public disclosure will cure the body politic. What if, Coetzee asks, the *Oedipus* story is itself a screen for the darker, more inexpressible truth that some people actually can just move on? “What if the true secret,” Coetzee writes, “the inadmissible secret, the secret about secrets, is that secrets can be buried and we can live happily ever after?” (2015, p. 34).

Both I and my Australian friend whom I quoted saying she had more to say were encouraged by institutional medicine, family, friends, and work places to regard our time with cancer as something that could effectively be buried; we could now live happily ever after. I later called that attitude the restitution narrative (Frank, 1995/2013). That works for some people, at least for a while, and those people will find little interest in what I have to say. I don’t want Coetzee’s argument to go away—it deserves to remain here in the room, troubling us. But for me—to pursue the Oedipus metaphor—a plague continued to darken my life, and to dispel that I needed writing as an attempt to tell the truth of about illness.

Let me focus these meandering remarks into three points. First, people who have suffered a trauma like deep illness need companions, and many will eventually need to fashion their own companions. I say *fashion* our own companions rather than *create* those companions, because my years have studying stories have convinced me that speaking of *creativity* risks setting up an unrealistic expectation and a misperception. We humans are creative, but our creativity is in fashioning something out of the resources we find available to us. Perhaps humans are best thought of as *dependently creative*.

Second, one aspect of that dependency is that fashioning companions requires resources. Here, we reach a sort of paradox. People are deeply committed to thinking of the stories they tell about themselves as their *own*; that can be a personal commitment, a group commitment, or both. But, humans tell stories by reconfiguring others’ stories. We are narrative magpies, making our nests from stuff that’s been left lying around, and there is an ethics to acknowledging that. To quote Coetzee again, he expresses skepticism about whether “each of us has a life-story, and we should exert ourselves to become the author of that life-story” (2015, p. 44). He does not spell out exactly what he means, so I will interpret it in terms of my own belief that even the most personal story is a reconfiguration of other stories. We are less authors and more like cut-and-paste editors of a life story we call our own. But, and crucially, over time we become deeply committed to that story as being our own. Our life stories are like clothes well worn to shape and express our bodies, with their off-the-rack origins forgotten.

Here is a sort of metaphor for so-called creativity. I once heard the educated judgment that Impressionist painting would never have been possible without the invention of the tin tube, because prior to that, paint had to be stored and carried around in pigs' bladders, which were prone to bursting. Individual impressionist painters were geniuses, but the expression of their genius—specifically, working in outdoor light—depended on resources including the humble tin tube. For storytellers, our tin tubes are the availability and recognizability of plot lines, character types, metaphors like the journey and the shipwreck, and the other cultural stuff out of which people are able to make up stories that other people will be able to understand. I was able to write *At the Will of the Body* because I had read enough illness memoirs to give me fragments of a model for how to tell a story like that, and because publishers recognized a category for books like that and had a sense that such books could sell. Once the book was out there, it became part of the stock of cultural resources available to future memoirists of illness, and thus the resource pool changes. I would like to say it develops.

My third point about writing raises the most complex issue of all: when people tell stories of traumas in their lives, they seek to tell the truth. A very great deal more could be said about that; *truth* is one of our densest words. Susan Gubar begins her book *Reading and Writing Cancer* by asking a question that is not at all rhetorical—it requires an answer—but neither is it ever resolvable: “How is it possible to write truthfully about intimate experiences without embarrassing ourselves or marginalizing others” (2016, p. 6). Those are immediate problems of truth telling. My own gloss on the truth problem is this: When powerful cultural narratives both proscribe telling some truths and prescribe what else is truth, and when memories of events are so drug-addled and multi-perspectival, and when not even you yourself entirely wants to remember the truth of what happened (much less do others want to hear it), how can you discover a truth that others can tolerate hearing and that you can live with? Because the story you tell will become the experience you then live with, not necessarily forever, but durably.

While I wrote *At the Will of the Body*, it mattered crucially to say things about the experience of cancer that were systematically suppressed by both medical discourses and what healthy civilians were willing to recognize. What disturbs me is that during the final editing process, I recall being troubled by how much I was giving up to the publisher's demands that I soften aspects of my descriptions. But once the book was published, and after I had done fairly extensive public readings from the book, the way it was written *became my memory* of illness. Therein lies the dilemma. Truth is expressible only in a particular telling, and representation always carries the guilty conscience of alternative tellings that it suppresses. The problem of truth and truth-telling leads directly to problems of doing health care research, but let me delay that with the briefest comments about an issue that needs to be raised, the therapeutic value of telling the story of one's illness.

3. Telling and healing

There seem to me to be four crucial ways in which telling a story about trauma in one's own life makes a difference in being able to live with that trauma. The sum of these differences is as close as I can get to evoking *healing*, a word I will never truly understand.

First, telling a story of suffering establishes some *distance* between the embodied immediacy of that suffering and the description of what is happening to a character in the story being told. I again quote Gubar: “The writing process, in its creation of an exterior expression of the self, resembles other therapeutic activities available to people whose physical strength is impaired: painting, for example, or playing an instrument” (2016, p. 4). Gubar proceeds to argue for what I'll call the democracy of writing; among different expressive media, writing is what most of us learn early in life and have most readily available. This exterior expression of the self is also what Gubar calls a “reconstitution of the self” (2016, p. 4). Here, she tells a fundamental truth: “Surgery, radiation, and chemotherapy can cause patients to feel so invaded, so bombarded, so infused that they lose a sense of their own agency, of subjectivity, even of language” (xiv). That is Gubar's version of finding herself in Dante's dark wood.

Second, storytelling palliates suffering by endowing reality with the quality of *subjunctivity* (Mattingly, 2014, p. 226, n. 2), as in the subjunctive voice of might-be or might-have-been statements. Stories' dramatic effect depends on listeners sustaining a background recognition that the story could always be told differently. There are almost always alternative ways of experiencing what is going on, and events could always have turned out differently. In its inherent subjunctivity, storytelling can open up a space of alternative possibility. That is palliative. It heals.

Third, stories *communalize* suffering. Because stories engage listeners, storytelling generates communities of vicariously shared experience. For those who suffer, storytelling is a way out of isolation and way into alliances. Stories turn loneliness into affiliation. This community may be a transitory moment of someone listening, or the listener may stay around and attend to retellings of that story and others. Stories humanize because they can communalize what has been far too private.

Fourth, and maybe most complex, stories can be a medium of *forgiveness*. The argument is complicated, but prolonged suffering engenders a sense of guilt in the person who suffers. Irrational as this guilt may be, it is the deeper and more insidious sense in which suffering stigmatizes. Complementary to that sense of guilt is a sense of resentment toward others who did not prevent the suffering in the first place and then were slow or inadequate in their responses to suffering. The dual nature of suffering, I believe, is to be both self-blaming and accusatory. These are the darkest qualities of suffering, and the most difficult to heal. Stories can be the beginning of forgiving both oneself and others. How that process works repeats the cycle I have been sketching: first opening up distance; then subjunctivity and its sense that what happens in one telling is only one among multiple possible tellings; and then creating community, in which those who were resented become allies in a shared story.

4. Health care research

On health care research, I risk sounding both polemical and grumpy. My problem is that after decades of laboring to bridge the issues I have been discussing with the world of research, I still see the same gap that was there when I began. I'll again frame the issues autobiographically. When I began writing *At the Will of the Body*, I already had a longer term research plan to make it the first of three books. The first was my own memoir; the second, which became the *The Wounded Storyteller* (Frank, 1995/2013) would be a more analytic study of illness stories and issues of narrating illness; and the third was to be about healthcare policy. That third idea changed into what eventually became *The Renewal of Generosity* (Frank, 2004), which is about the ethical foundations that I believe any policies have to be self-reflectively based on.

I wanted to begin this project with a memoir mostly because, as I said earlier, I had truths I needed to tell and a self I needed to write back into being. But I also anticipated a future research ethics problem. If I was going to build a career from telling other people's illness stories, the least I could do was to make my own story equally available for retelling. Retelling others' stories invariably risks appropriation. But we often forget that the other side of appropriating is to risk leaving a story unheard and isolated from other stories among which it would gain greater effect. Either way, there is risk. A privilege I have enjoyed as an academic is having an audience. In telling others' stories to my audiences, either live or in print, I do appropriate those stories by putting them in contexts I choose. But the alternative is to leave those stories untold, unwitnessed. The line between being one who appropriates and one who witnesses is very fine indeed.

As to research itself—what to write and how to write—the advice I return to constantly was offered to me in 1992 by a woman at a meeting of the cancer support organization of the M.D. Anderson Cancer Center in Houston. It was a big meeting; never in the years since then have I been among so many people living with cancer. *At the Will of the Body* had just been published, but this woman had already read it. She looked like she had been through multiple cancer treatments. She

held me by the sleeve—a bit like the Ancient Mariner stopping the wedding guest—and told me, first, that everything I'd said in the book were things she had already noticed and understood about illness and treatment. But, she then added, she couldn't have said those things herself. She could not have put her recognitions into words. Then she gave me a beaded keychain she had made. That was her hobby, doing craft beading and giving her creations to people she valued. That gesture remains with me, almost 25 years later.

Hearing her, I had an immediate let-down when she said that I—a sociologist—hadn't noticed anything in institutional medicine that she hadn't noticed. But the second point of her message—that she herself could not have put her recognitions into words—gave me a new sense of vocation in research. We researchers invest far too much importance in the idea of discovering. We seek to create a distance between common sense or folk beliefs and our findings, which we present as privileged interpretations. I find that frustrating and less than useful. There's a quotation from Albert Camus that I came upon early in my career, in which he says that our task as privileged intellectuals is to speak on behalf of those who cannot. That is the first, crucial question I want to pose to any healthcare researcher: *How have you spoken on behalf of someone who understands a fundamental truth about their life and work, but who is without resources to be able to give that understanding public articulation?*

What frustrates me in published health care research is that the voices of ill people and healthcare workers are given so much less space than all manner of broiler-plate about method, which is essentially professional self-legitimation. Research too often subsumes people's voices, instead of offering itself as the platform for such voices. On my account, the first task of research is to empower people to speak. If those voices are compelling, then the method of how those voices were selected and conditions in which they were heard is not irrelevant, but it belongs as a note after.

The social science I read today that teaches me most are book-length ethnographies in which discussion of method is placed in an appendix. Journal research needs to look for its model to books that tell the stories of people's lives, based on the researchers having immersed themselves in those lives. To do that, qualitative research has to get back to field observations and de-center interviews, especially interviews held in academic offices. When I was developing *The Wounded Storyteller*, I was talking to ill people in support groups and in clinical settings. In those settings, people tell truths that offices can inhibit. People tell different stories in different settings, because the setting cues the story. Office interviews have their place, but I believe they make sense only in the context of more participatory methods.

To put this positively, I want to see *witnessing* become, if not exactly a recognized research method, at least a fully legitimate rationale for doing and presenting research. I want to see researchers understand themselves not as privileged coder/interpreters of their participants' stories that are now *data*, but rather as witnesses who *serve* their participants by *amplifying* voices that would otherwise be silent, and *connecting* in solidarity voices that are otherwise isolated. I repeat, research should be a work of service that serves by amplifying and connecting voices. These should be both the voices of ill people and the voices of health care workers, including the often maligned administrators, who have problems too. All these people, like the woman who took my arm at the meeting of cancer survivors, know quite well what they are going through. Although, it is a human tendency to ignore what those next to us are going through, and how we affect that next person's experience.

For people to have an illness of their own, we need a health care research that takes witnessing as its responsibility and opportunity. People who find themselves lost in a dark wood need not a Newton, but a Virgil.

Funding

The author received no direct funding for this research.

Author details

Arthur W. Frank^{1,2}

E-mail: arthurwfrank@gmail.com

ORCID ID: <http://orcid.org/0000-0001-6345-2387>

¹ Professor Emeritus, University of Calgary, 5904-84 Street N.W., Calgary, Alberta, Canada T3B 4X5.

² VID Specialized University, Oslo, Norway.

Citation information

Cite this article as: An illness of one's own: Memoir as art form and research as witness, Arthur W. Frank, *Cogent Arts & Humanities* (2017), 4: 1343654.

References

Alsop, S. (1973). *Stay of execution: A sort of memoir*. Philadelphia, PA: Lippincott.

Coetzee, J. M., & Kurtz, A. (2015). *The good story: Exchanges on truth, fiction, and psychotherapy*. London: Harvill Secker.

Dante, A. (2013). *The divine comedy* (C. James, Trans.). New York, NY: Liveright.

Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems & Health*, 16, 197–212. <https://doi.org/10.1037/h0089849>

Frank, A. W. (2001). Can we research suffering? *Qualitative Health Research*, 11, 353–362. <https://doi.org/10.1177/104973201129119154>

Frank, A. W. (1991/2002). *At the will of the body*. New York, NY: Mariner Books.

Frank, A. W. (2004). *The renewal of generosity: Illness, medicine, and how to live*. Chicago, IL: University of Chicago Press. <https://doi.org/10.7208/chicago/9780226260259.001.0001>

Frank, A. W. (2005). What is dialogical research, and why should we do it? *Qualitative Health Research*, 15, 964–974. <https://doi.org/10.1177/1049732305279078>

Frank, A. W. (2010). *Letting stories breathe: A socio-narratology*. Chicago, IL: University of Chicago Press. <https://doi.org/10.7208/chicago/9780226260143.001.0001>

Frank, A. W. (1995/2013). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.

Gubar, S. (2016). *Reading & writing cancer: How words heal*. New York, NY: Norton.

James, C. (2015). *Sentenced to life*. New York, NY: Liveright.

Lorde, A. (1980). *The Cancer Journals*. San Francisco, CA: Spinsters/Aunt Lute.

MacIntyre, A. (1984). *After virtue*. Notre Dame, IN: University of Notre Dame Press.

Mattingly, C. (2014). *Moral laboratories: Family peril and the struggle for a good life*. Berkeley CA: University of California Press. <https://doi.org/10.1525/california/9780520281196.001.0001>

Pullman, P. (2000). *The amber spyglass*. New York, NY: Knopf.



© 2017 The Author(s). This open access article is distributed under a Creative Commons Attribution (CC-BY) 4.0 license.

You are free to:

Share — copy and redistribute the material in any medium or format

Adapt — remix, transform, and build upon the material for any purpose, even commercially.

The licensor cannot revoke these freedoms as long as you follow the license terms.

Under the following terms:

Attribution — You must give appropriate credit, provide a link to the license, and indicate if changes were made.

You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.

No additional restrictions

You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.



Cogent Arts & Humanities (ISSN: 2331-1983) is published by Cogent OA, part of Taylor & Francis Group.

Publishing with Cogent OA ensures:

- Immediate, universal access to your article on publication
- High visibility and discoverability via the Cogent OA website as well as Taylor & Francis Online
- Download and citation statistics for your article
- Rapid online publication
- Input from, and dialog with, expert editors and editorial boards
- Retention of full copyright of your article
- Guaranteed legacy preservation of your article
- Discounts and waivers for authors in developing regions

Submit your manuscript to a Cogent OA journal at www.CogentOA.com

