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Can We Research Suffering?

Arthur W. Frank

Illness troubles us because it is an occasion of suffering, but research on illness has difficulty conceptualizing suffering—and naturally so because suffering is not a concept but a lived reality that resists articulation. Based on the work of Dorothy Smith, the author argues that the rhetoric of social science inadvertently increases suffering because it attempts to organize local experience within extralocal categories. He concludes with suggestions for changing research practices.

Let me begin by contrasting two illness experiences of my own; this contrast is the first in a sequence of attempts to specify this most elusive quality, suffering.¹ The discussion I hope to initiate begins with the idea that suffering is what makes illness worth studying, just as illness is what makes health care a topic of concern. I propose that research has a problem encountering suffering, and in its evasions of suffering, research can create more suffering for ill people. I begin with my own suffering.

Just more than 6 years ago after an annual follow-up examination for cancer, my chest X ray showed lymph nodes on my lung and diaphragm. I was used to false positives on these tests, but then a computed tomography scan showed more nodes than the X ray had. My response to this news depended on the centrality in my life of thinking and writing about illness. My first book (Frank, 1991), a personal narrative of my experiences of heart attack and cancer, had been out for several years. I was speaking regularly to illness support groups and to medical groups and putting together the ideas that would culminate in my second book (Frank, 1995). I had immersed myself in the narratives of people who had lived their illnesses in the most exemplary ways; I saw my task as the amplification of the lessons they had left us. This work had rendered me prey to a tacit belief that illness could not surprise me. I learned how wrong that was. When the call from the hospital was for me and the scans on the wall were mine, I was surprised, afraid, and I suffered.

Fortunately, I did not forget everything I had learned during the previous years. One thing I remembered was to ask myself, in a meditative way, what I was suffering from at that immediate moment. The answers were all memories and anticipations because at that moment I did not feel sick. I would learn from a later biopsy that I was sick but not with cancer. The sickness I had—an inflammation of the lymph system called sarcoidosis—would never have been diagnosed if I had not

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been followed for cancer. Sarcoidosis can be a very serious disease, but my case had no effect on how I felt. I called it my virtual illness.

During the month between getting the bad news of the irregular chest X ray and receiving the good news about the biopsy, my paradoxical condition was to enjoy very good health in the verified presence of serious illness. I experienced the suffering of illness without experiencing any disease. My bizarre confluence of circumstances turned that month into a controlled experiment in pure suffering.

I contrast that experience to a recent attack of tendonitis in my shoulder. The tendonitis caused extraordinary pain—the least movement seemed to rip my shoulder apart, and I realized what a horror the rack was as an instrument of torture—but I knew what was happening and had reasonable assurance that the acute phase would not last long. The pain lasted a couple of months, especially at night, but once I knew there was no damage requiring surgery, the pain was nothing more than pain. I had no particular plans that involved more than the minimal use of my shoulder. So here is the reverse experiment: pain with more annoyance than suffering.

My point in contrasting these two experiences is not to reaffirm a common dichotomy between pain as purely physical and suffering as beyond the physical. The writings of David Morris (1991, 1998) on pain convince me that dichotomy is particularly deceptive on the pain side because Morris convincingly demonstrates how culture affects pain. Pain is not just physical.

My contrasting illness experiences convinced me there are dichotomies, but these are within the category of suffering. These dichotomies began in my feeling of being disconnected from my life as I had been living it and from the lives of those around me. Suddenly, they (including my recently healthy self) were standing on one shore, and I was in a small skiff being carried toward an opposite shore. I could still call to them and they answered, but the distance separating us was growing rapidly. In contemporary academic usage, I was becoming other to the person I had been and to those who knew that person. The feeling of becoming other has nothing to do with social support—I had generous support. It was precisely my high quality of support, along with my absence of pain or physical distress, that placed my suffering in such stark relief. My sense of being set apart had nothing to do with any material resource I could imagine having had.

Let me tell a story that illustrates this sense of disconnection and begins to suggest why suffering is so difficult to define and to research. As part of the preoperative routine before my biopsy surgery, I was interviewed by a nurse who asked me, at the end of her inventory of required questions, how my wife and I were coping with my possible cancer. I told her that we had a new baby, my wife was still recovering from a difficult pregnancy and birth, and we were doing very badly indeed. Her reply confirmed my worst suspicions about medical pretenses to caring and also taught me much about suffering. "You have to talk to each other," she admonished as she closed her clipboard and left. End of interview; no follow-up was offered. Of course she was right; we certainly needed to talk to each other. But our suffering was why we could not talk. Our suffering was what we could not say. We feared saying what we felt, and we feared our words could never convey what we felt but would reduce those feelings to complaints and specific concerns. "Don't you know," I wanted to shout to that nurse as she walked away, "it's what your patients can't say."

Suffering involves experiencing yourself on the other side of life as it should be, and no thing, no material resource, can bridge that separation. Suffering is what lies beyond such help. Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of no thing, an absence. We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be. At the core of suffering is the sense that something is irreparably wrong with our lives, and wrong is the negation of what could have been right. Suffering resists definition because it is the reality of what is not. Anyone who suffers knows the reality of suffering, but this reality is what you cannot “come to grips with.” To suffer is to lose your grip. Suffering is expressed in myth as the wound that does not kill but cannot be healed.

Now I want to offer the sweeping generalization that if illness did not involve suffering it would present only a technical, instrumental problem, and the only rationale for nonbiomedical research would be the enhancement and quality control of medical services. In the case of my tendonitis, the medical model worked well: isolation and diagnosis of the specific problem, clear presentation of treatment options, and support in the option chosen. All I needed were good doctors and good physiotherapists. If all illness was of this kind, research could be purely adjunctive to medical professionals doing their work as they define it.

But most illness does involve suffering, and the medical model, so potent against what can be located, identified, and acted upon, is equally impotent against suffering that resists location, identification, and action. As an organized enterprise, medicine’s war against suffering is like Napoleon’s invasion of Russia; the enemy continues to withdraw while the conquering army becomes increasingly hungry, flea- and frostbitten, homesick, and depressed. The problem—which I hope my contrasting illness experiences illustrate—is that suffering has no necessary connection to illness. Illness is only one occasion for suffering. Individual medical professionals certainly engage their patients’ suffering and can diminish it, but I suggest that they do so by working outside the biomedical model. My present concern, however, is not medical professionals but researchers.

My case that qualitative health research has difficulty encountering suffering begins with a critique presented by Dorothy Smith (1999), describing the rhetorical form of sociological texts. The book she refers to happens to be about soccer violence, but “the young men” she talks about could just as well be the sample in a study of some disease:

At the beginning of the book, they describe the young men they studied as the “*dramatis personae*.” The metaphor expresses exactly the sociological relation created in the text. Respondents have the appearance of free agents. They have the appearance of speaking with their own voices. But, in fact, the sociologists’ script prescribes how they appear and what they say. The sociologists speak through their *dramatis personae*. Standpoint has effectively been conceptually shifted from that of the young men with whom they talked, and whose viewpoint they wanted to make central, back to the standpoint of the discourse locating the reading subject in the relations of ruling. (p. 67)

This passage troubles me because it describes work I have done myself, work I have refereed and reviewed, and work I have supervised.

Smith (1999) describes how “theory is deployed to pick out and tailor extracts from the original events to appear conceptually reconstructed or as fragments of speech or writing sustaining the discursive project” (p. 141). What is wrong with such work begins with the respondents who are thus fragmented and reconstructed. During a session at the 1998 meeting of the American Sociological Association, I invited a friend in the audience, Shelly Diamond, to respond to a discussion about the ethics of such conceptual reconstruction of respondents. She spoke eloquently about how disrespected she felt when she read the research reports that included her responses to an interview study concerning her particular illness. What insulted her was the fragmentation of her story described by Smith. Bits of her story were made to reappear as instances validating whatever point the social scientist was making in that particular chapter.² The literal integrity of her story was sacrificed to generate the apparent integrity of the social scientist’s narrative. If only the feelings of respondents were at stake, the issue would be serious enough but not, I think, as serious as it is.

Many qualitative researchers would reply to Smith (1999) that what she calls the script is not the sociologist’s creation—as Smith claims it is—but is inductively derived from the respondents themselves. Researchers seek to reassure themselves of this by taking the script back to the respondents to verify that they recognize it as theirs, thus guaranteeing that it is not being imposed on them. For all that gesture has to recommend it, I believe it fails to understand what is crucial for Smith. If the sociological text that respondents are being asked to approve is, as Smith contends, an extension of the relations of ruling in which those respondents are already embedded, then their approval might signal their resignation to the inescapability of those ruling relations: They offer not assent but capitulation to the authority of social science. To explain this interpretation, I turn to what Smith means by ruling relations.

In the long quotation previously cited, Smith (1999) presents a dichotomy between two standpoints. On one side is the standpoint of the young men who were the respondents—for our purposes, this is the standpoint of those who suffer. On the other side is the standpoint that Smith calls *discourse*, specifically “the discourse locating the reading subject in the relations of ruling” (p. 67). What then is Smith’s particular use of discourse, and how do ruling relations work through discourse? What is at stake in these questions is whether qualitative research can enhance a recognition of suffering in society or whether research becomes, however unconsciously, an organizing practice through which medicine and society can avoid recognizing suffering.

By *discourse*, I understand Smith (1999) to mean extralocal texts—texts created elsewhere—that organize action and relationships in local settings by instructing actors in those settings as to what they should do and perhaps proscribing what they cannot do. In medicine, diagnostic-related groups (DRGs)—by whatever subsequent name they are known—are a prime example of discourse (Dolenc & Dougherty, 1989). DRGs are written documents, created by a group of specialists working on the basis of individual clinical experience and aggregate data but working apart of any specific scene of clinical practice. These specialists produce a code of diagnosis—all illnesses must map into DRG categories to be treated—and detailed specifications of what count as reimbursable services for each category. DRGs, as textual code created elsewhere, thus organize activity in local clinics.

People in local settings still make decisions and deliver care, but the text limits and directs what they do. Of course, treatments and services not specified in the DRG can be offered or recommended, but then someone has to absorb the cost, setting in motion another round of negotiations with reference to other texts (legal liabilities, for example). When Smith writes that “ruling relations appear as abstracted systems, hooking up local events with extra-local organizational forms” (p. 32), discourses like DRGs do the hooking up. She describes discourses as a “bridge” (p. 7) between the everyday (local) and the ruling relations (extralocal). What then are these ruling relations?

Smith (1999) is clear that by *ruling relations*, she does not mean a class or any specific individuals, although some individuals and groups clearly benefit from a given system of ruling relations. People write texts, but texts work by implicating other texts: DRGs refer, on one side, to hospital budgets, physicians’ compensation agreements, and multiple managed care contracts; on the other side, DRGs encounter both legislative codes of health care and professional standards of practice. Such a textual web of extralocal discourse goes beyond the intention, even the control, of any individuals or groups. Smith writes that ruling relations are “not yet monolithic” but are “pervasive and pervasively interconnected” (p. 49); their power lies in their interconnection. Ruling relations organize local settings through the medium of discourses and are themselves the effects of that textual organization. Ruling relations make extralocal imperatives appear under such rubrics as *rationality*, *efficiency*, and perhaps most relevant to social science, *objectivity* (see Smith, 1999).

I can now return to Smith’s (1999) complex sentence, quoted above: “Standpoint has been conceptually shifted from that of [the respondents] . . . back to the standpoint of the discourse locating the reading subject in the relations of ruling” (p. 67). As part of their organization of local settings, texts organize how they themselves are read. The reader—whether medical professional or patient—is required to adopt the extralocal perspective from which the text makes sense. Through the dominance of this perspective, Smith writes, “The stylistics of universality are preserved against the threat of fragmentation and disorder” (p. 153). This threat—and I will speak later about suffering as a prime example of such threats—is that the problematic of the local situation might challenge the organizing effect of the text. Texts that meet such challenges must do more than tell local readers what actions to undertake. Texts must also alter the standpoint of local readers, who are taught by the text to dismiss such challenges. The stylistics of universality endow readers with the extralocal relevances of ruling relations. Such relevances dictate ignoring what is now merely local, such as suffering.

The reader’s reward for this shift in perspective is to become a privileged interpreter of the extralocal text and thus be empowered to trump those who speak from the merely local perspective. If the local does not fit the organization prescribed in the text, that sense of disjunction is to be disregarded. “No feeling other than that prescribed is admissible to the dialogue within the text,” Smith (1999) writes, “and the reader as the text’s proxy is enforcer of that rule” (p. 152).

Smith’s (1999) critique of sociological texts is that they perpetuate the stylistics of universality and rewrite local observations into extralocal texts. The privilege that methodologists and theorists afford to generalizability effects this trans-

formation: The only allowable observations are those in which the local is read as an instance of the universal, and traces of contingency are excluded.

As I understand Smith's (1999) critique, research aspires to the extralocal standpoint that she calls discourse, and it is the adoption of this standpoint—before anything substantive is said—that perpetuates relations of ruling. I can now return to my earlier objection that taking the sociologist's script back to respondents for their approval proves little about whether that script expresses their own standpoint. Most respondents have already been trained by a lifetime of living within the standpoint of discourse to recognize the proper form of social science texts; the resistance of Shelly Diamond at the American Sociological Association meeting is the exception. That respondents do recognize themselves in the social science scripts attests only to the power of ruling relations. Respondents' approval of scripts is little more than resigned acceptance of what they already knew social science does: organize their local experience into extralocal categories in which their lives and their suffering effectively disappear.

When other actors in other local settings read the research report, the effect is to teach them to see the particular people they work with and care for as instances of the general categories presented in the report. The person becomes the contingent embodiment of the universal. This method of reading fits perfectly in the clinic, where diagnosis depends on the same interpretive process. Diagnosis understands the universal form of the pathology as contingently embodied in the patient at hand; that patient is perceived as an instance of the universal. The person is transformed into a patient when the diagnostic category is appended to his or her name. During one of my hospitalizations a nurse, speaking to my wife without discernable irony, actually did refer to me as "the seminoma in 53."³

"So what's wrong with it?" a defender of this research or clinical system might reply. Many people would regard the process I have described as what both science and management require. The opposite question is what these systems exact from those within them. Smith (1999) assesses the cost in the persistence of patriarchy. Her concern is that the movement from local to extralocal involves the erasure of the everyday work, problems, and perspective of women. Imposing the stylistics of universality means refusing to see gender difference. I want to describe a complementary dimension of costs. My problem is the erasure of suffering from illness. Smith (1987) sees women existing on the wrong side of a "line of fault" (p. 49 ff) that is placed between their experience in local settings and the extralocal version enforced by ruling relations. I see ill people experiencing a similar line of fault as their lives are assimilated and described not only by medicine but also by social science.

The problem for ill people is ruling relations' insistence that all can be spoken; the nurse who said that my wife and I must talk to each other expressed this insistence. Research is one practice—psychotherapy is often another—in which ruling relations demand that all be spoken. Such research organizes suffering by making it reappear as categories that may all be valid enough for what can be spoken, but they refuse to acknowledge that aspects of suffering remain unspeakable. Suffering, the mute embodied sense of absence, both eludes extralocal categories and threatens the standpoint of discourse that supports those categories. Suffering threatens discourse because discourse cannot assimilate it to extralocal demands. When expressions of suffering break into discourse, the reader is returned to his or her own

contingent embodiment in all its locality. When one's own body is attended to, the textual spell of the extralocal is broken.

Here I return to my own experiment in pure suffering, as I called it. One response to my situation might be to ask why I did not seek help, counseling perhaps. My best account for why not involves a paradox of suffering: While I certainly did not wish to suffer, suffering was also the embodied reality, the truth, of my situation. Some part of my integrity was to suffer; not to have suffered would have been to fail to experience myself fully in the situation I was in—facing a recurrence of cancer. My integrity did not require that I suffered, but it required that if I was to suffer I encounter my suffering. I feared professionals who were unable to encounter suffering as the hole—the unspeakable and perhaps the incomprehensible—in what they could say and do. I feared them seeking to explain me as an object of suffering, rather than remaining silent in the face of what they could not speak.

I propose that the problem of suffering is not how we know it but how we encounter it. I follow the philosopher Emmanuel Levinas (1985, 1989, 1998) in understanding suffering as a call; to encounter one who suffers is to feel called to respond. As I understand Levinas, even the substantive noun *suffering* should be suspect. The only reality is the face—the embodied humanity—of the person who suffers. Levinas teaches, perhaps more clearly than anyone, that this responsibility to recognize and respond to suffering is emphatically not to pretend to know the other's suffering. As Robbins (1999) writes, for Levinas, the other "is not under a category. He is the one to whom I speak" (p. 10). To place the other under a category is, for Levinas, a form of symbolic violence against the other. A claim to know the other's suffering takes away part of that other's integrity. An appropriate Levinasian model of response to suffering would seem to be Job's friends during the 7 days and nights while they sit with him in silence, before they begin to interrogate him.

A researcher might respond to Levinas, "What do you want from me?" The task of research is to specify the conditions that cause suffering so that these conditions can be changed to lessen suffering. The task of the researcher is not to sit in silence with Job but to find out how he got onto the dung heap so that others can be kept off similar dung heaps. Research seeks to find what resources Job may need to get himself off his dung heap. Research can claim that it is empathic and compassionate, whereas Levinas's emphasis on the absolute alterity of the other—the unknowable nature of the other's suffering—seems distant, even cold. For all Levinas's talk of responsibility for the other, he seems to create a greater distance from that other's situation and the possibility of changing it.

This response to Levinas would make sense if one accepts its fundamental premise. This premise is given ironic expression by Jean Baudrillard (1998), writing about the logic of consumer society in which every desire is assured of finding a corresponding object that can bring satisfaction. Failures of satisfaction can never be acknowledged. "All the things [that] do not fit into this positive vision," Baudrillard writes, "are rejected, censored by satisfaction itself . . . and no longer finding any possible outlet, crystallize into a gigantic fund of anxiety" (p. 177).

Research that proceeds from the standpoint of discourse within ruling relations has its own version of Baudrillard's (1998) "positive vision." Research places whatever cannot be operationalized, objectified, and rewritten within the stylistics of universality among "all the things [that] do not fit". Whatever cannot be reinscribed as an instance of some extralocal category must be rejected and censored. The

standpoint, not the intentions of the individual researcher, dictates this rejection. The question might be asked whether research cannot do what it does—be the extralocal organizing of local experience—and leave Levinasian response to suffering as someone else's responsibility. Baudrillard teaches us that research, to sustain its own logic of satisfaction, must reject and censor the Levinasian response as unnecessary because the contingent particularity of that response places it outside the ruling relations. Response to the other who suffers is a moment of consummate locality, excluding any extralocal categorization.

Research's positive vision necessarily ends in the clinic by censoring suffering itself: telling the ill person that she or he has no further cause to suffer or that her or his needs are being cared for and believing care is complete because a network of texts including research has guaranteed its completeness. During my controlled experiment of pure suffering, all my needs were being met, yet I suffered. My suffering had little to do with needs. I was not in need but in mourning, grieving the life that I might not live as well as what I might be forced to live and what my family might be forced to live with me. The disconnection of my suffering would only have been made worse had some professional assured me that my needs were being met. The censoring of my suffering would only have added to my already gigantic fund of anxiety, just as Baudrillard (1998) writes.

Ruling relations provide assurance, from their extralocal omniscient site, that local needs are being met and there is no reason not to feel satisfied. All the things that do not fit this assurance are, as Baudrillard (1998) said, censored; the text allows no space for their presence. Smith (1999) makes the same point when she writes, "The dialogue interior to the text offers no purchase to the challenge offered by counter-examples" (p. 152) and later when she describes "the power of a theoretical text to insulate the discourse against subversive voices" (p. 155). Suffering is the subversive voice in the biomedical discourse; it is central among all the things that do not fit. Social science and biomedical discourse perpetuate this censoring when they reduce suffering's embodied locality to extralocal categories that organize responses. Clinicians informed by such discourse respond not to the person who suffers but to the person viewed as an instance of a type of suffering that the text has taught the professional to recognize.

Any concluding prescriptions of new ways of doing qualitative health research risk becoming more extralocal organizing of your local practice, but we all need some principles through which we can reflect on our practices. Smith (1999) offers one especially clear guideline when she writes, "The aim is not to explain people's behavior but to be able to explain to them/ourselves the socially organized powers in which their/our lives are embedded and to which their/our activities contribute" (p. 8). Too much research on illness rewrites their and/or our lives as behavior to be explained: coping, giving and receiving support, denial, adherence (the more politically correct name for the old compliance), even grieving all become behaviors to be explained as functional and adaptive with reference to clinically normative standards. Smith advocates a different aim: not explaining respondents' behavior to experts but explaining social systems to respondents so they can understand the powers in which their lives are embedded.

A complementary aim of research, less ambitious social scientifically and closer to my own previous work, is to use academic privileges of publication and platform to amplify the voices of the ill themselves, offering them previously unrecognized

connections and a sense of community. Insofar as my work does employ organizing categories, I have sought to construct categories that do not explain ill people's experiences and their stories. The aim of mapping stories is to allow ill people to connect their stories to others and perhaps to recognize what stories they have not yet told. A complementary aim is to offer professionals an enhanced sense of the different stories people tell; to get them to think less about these stories and more with these stories (Frank, 1995). Sometimes, thinking with the story means listening to silence, to the story that resists becoming a narrative.

Whatever aim research seeks, the researcher cannot evade the responsibility of first encountering suffering and then keeping the specificity of that encounter at the center of the project, refusing to assimilate that encounter to extralocal organization. The aim of research is to oppose the censoring of all the things that do not fit. The perpetual dilemma is how to recognize those things—which means writing them—without making them fit some explanatory schema. Here, I return to Levinas's issue of alterity and his exquisite attention to the risks of symbolic violence. We never resolve this risk; we only balance on the edge of it. Research is always caught between the imperative to speak, which risks reinscribing the local under some extralocal category, and the equal imperative to recognize but remain silent. Yet silence, however respectful, risks abandoning the field to the standpoint of extralocal discourse. The censoring of what does not fit remains unchallenged.

As much as I care about these issues, I realized as I finished this article that I wrote it because of something unresolved about my suffering 6 years ago as I waited for confirmation of some diagnosis. What threatened me most was not only cancer itself—although that was threat enough—pain and disruption were real threats, and especially when cancer recurs, death is a threat. But I suffered at the prospect of what I could call *going back into it*. I suffered at having to submit my suffering to medical workers for whom I was another instance of a category requiring that this and that be done. In treatment, I knew I would become a task that workers would have to address as one of a series of tasks that were part of a working day. I would be something else to get done. Being treated that way is tolerable when I do my banking or get my driver's license renewed; I expect to be treated that way. But to be treated that way when I am suffering turns my suffering into one of the things that do not fit. And because, to be a good medical treatment citizen, I have to pretend I share the premises of the system, my censored suffering "crystallizes into a gigantic fund of anxiety," just as Baudrillard (1998) aptly described it. That compounding of suffering is what I dreaded.

I need to offer an ending that affirms how the work we share can continue. My point has not been to speak against research; what I have said seeks only to broaden discussion about how research continues. Let me close with a last story about why, however real the power in ruling relations is, we each remain free. In my initial hospitalization for cancer in 1986, the best thing that happened to me was this. One day I had a painful diagnostic procedure. Afterward, a technician came into my room to draw blood. We got to talking while she worked, and she offered me some advice. "Remember," she said to me, "everyone who touches you affects your healing."

Research touches ill people. Qualitative researchers pride themselves on their personal encounter with ill people. Remember, how you touch them affects their healing, and your own healing too.

NOTES

1. For a discussion of previous definitions of suffering, see Frank (1995).
2. For her own telling of her illness experience, see Diamond (1996).
3. See Chambliss (1996) on the "routinization of disaster." Chambliss' discussion of "what it means to be a nurse" (pp. 62-68) contrasts the local relevances of nursing work with the extralocal categories that organize physicians' work.

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