

Virtual Mentor

American Medical Association Journal of Ethics
July 2011, Volume 13, Number 7: 503-506.

OP-ED

The Case History and Deferred Pain

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After giving a lecture at another campus recently, I was approached by a graduate student (whom I'll call "Joanne" [1]), who told me the following story.

At the age of 7, Joanne was operated on for a significant physical anomaly that has required ongoing medical attention. To help her cope with the onset of this regimen, she was sent to a therapist. Nearly two decades later, learning that the therapist had been appointed to a prestigious academic post, Joanne looked her up online out of curiosity. On the therapist's resume, she found an article whose title led her to believe it was about her case. She obtained the article and confirmed her suspicion. She found reading it deeply unsettling.

This anecdote illustrates, for starters, how the Internet has shrunk our world. We all have less privacy than we used to, and it is ever easier to trace others and references to ourselves. Scenarios such as Joanne's, however, do not require the Internet: in 2001 a psychotherapy patient queried the *New York Times* ethics columnist Randy Cohen after discovering what he (or she) believed to be his (or her) case narrative while browsing in a bookstore [2]. These stories reveal that, even when authors of case studies *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 this recognition is very likely to cause them discomfort.

These therapists presumably thought they had done everything required by ethical guidelines. Perhaps they had. Joanne was far too young to grant consent to her therapist; rather than seeking it from her parents, the therapist gave her a pseudonym to conceal her identity. At the same time, Joanne's youth may have led her therapist to dismiss the possibility of her ever reading the article. And before the Internet, her doing so was far less likely. But she did, and she readily recognized it as her own case.

In addition to the advent of the Internet, the adoption of narrative medicine can also increase the likelihood of scenarios like this. With a narrative approach—which, according to Rita Charon, elicits “accounts of self not limited to physical aspects of the body but that include emotional, familial, aspirational, creative aspects of the self”—a physician's relation to her patients moves closer to that of a psychotherapist [3]. This may serve the patients' interests; that is the aim (and claim) of narrative medicine. But greater knowledge of patients' lives also facilitates and encourages the writing of case studies. Indeed, in a paper delivered at the Modern Language

Association convention in January 2011, Charon, one of its foremost advocates, eloquently addressed the dangers 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 will only extend the power of clinicians [3]. It may also increase the risk of what I call “deferred iatrogenic pain”—emotional hurt inflicted on patients not by their treatment but by their case narratives.

The point is that even heeding ethical guidelines does not preclude the possibility that case histories will cause pain to their subjects. That pain may not rise to the level of manifest “harm,” and the clinicians may not have violated the precept “First, do no harm.” But in Joanne’s case, the pain was far from negligible, despite being long delayed. And it may have been avoidable.

Perhaps not; it may not always be possible to conceal patients’ identities from them. The very details that distinguish cases sufficiently for them to make a contribution to the medical literature may also enable patients to recognize them as their own. In any event, among the potential readers of case studies, patients (and those close to them) are uniquely equipped to know *all* the identifying details *and*, of course, who provided treatment.

If their rights have not been violated, the question is whether their pain is outweighed by the benefits of writing the narrative. The question *then* becomes *cui bono*? Who—or what—benefits? Presumably, the goal of writing case histories is to advance the understanding of particular conditions and improve their treatment. Thus, the case history serves the common good, the welfare of all—the public health. At the same time, there are undeniable personal and professional benefits to the *author* in committing a case to print. Doing so can build the author’s reputation and advance his career—and lead to monetary gain. Consider the example of Oliver Sacks, the world’s most famous neurologist, whose fame (and fortune) is based not on his record of treating patients or on his contributions to neurology but on his many nonclinical case studies of unusual syndromes [4]. So the medical professional may not be in the best position to judge the advisability of writing up a particular case. Indeed, the writing of case studies entails a conflict of interest: authors stand to gain from them in a way that is not true for their subjects. This can affect their judgment of the *medical* benefits of such projects.

I cannot speak for Joanne; indeed, she is struggling to understand just why she was so troubled by reading her case. But I think that a patient’s discomfort could 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 the hope of help—of *care*, if not of cure. To the professional, however, the patient represents an instance of something beyond herself, perhaps a disease or impairment in which the professional has an intellectual interest or is carrying out 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 a patient, but also a *case*—indeed a case *of*—to her therapist or physician. The psychotherapist Ruthellen Josselson has acknowledged this. Confronted with negative reactions by her patients 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 the interview 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 [5].

Thus, the patient who reads her own case may make the uncomfortable discovery that, in the therapeutic relationship, her well-being was not the *only* end: she has also been a *means* to an end. Whether she values that end depends 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 careerist, she may not.

I would advise medical professionals, then, to 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 has perhaps no idea what it would be like to come upon her story in alien discourse. So 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. And not to write, if one believes it will cause too much discomfort.

References

1. “Joanne” and I have spoken about her experiences and her story is used with her permission.
2. Cohen R. The ethicist: case study study. *New York Times Magazine*. November 11, 2001: 50.
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