

Virtual Mentor

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FROM THE EDITOR

Healing Narrative—Ethics and Writing about Patients

As Jack Coulehan and Anne Hawkins put it, “writing about patients is a growth industry” [1]. Recent years have seen an explosion of both fiction and nonfiction works written by physicians for a popular audience. Atul Gawande’s *Complications*, Pauline Chen’s *Final Exam*, and Danielle Ofri’s *Singular Intimacies*, all critically acclaimed and widely read, open a window into an experience that was once the sole province of those in medical training. These authors employ patient stories to convey poignant insights about what it is like to practice medicine. Neurologist Oliver Sacks’s classic *Awakenings* and more recent *An Anthropologist on Mars* also make use of patient stories, guiding his readers into the awe-inspiring world of the human mind through the unusual experiences of his patients. These powerful memoirs, however, move us to ask, whose stories are they telling? What are physicians’ responsibilities towards patients when they put them on paper? In this issue of *Virtual Mentor*, we explore the ethics of writing about patients and examine the sometimes conflicting, sometimes synergistic duties of physician and author.

Sharing patient stories has always been a mainstay of medical education—every issue of *Virtual Mentor* begins with three clinical cases. This is not an arbitrary quirk but a reflection of a long tradition. Clinicians share patient stories on the wards, in grand rounds, in doctors’ lounges; they tell patient stories to medical trainees and teach them the language in which to tell these stories themselves. Case reports have long been an important tool in the academic medical journal as a way to expose other physicians to unique, exemplary, or otherwise useful patient cases. For this reason, our first case starts on familiar ground: what are the ethical considerations involved in publishing a patient case in an academic journal? Ronald Pies and Judy Kantrowitz address the tension inherent between the duty to further therapeutic knowledge and the need to protect patient confidentiality. Although there was a time when the likelihood that patients and those who knew them would access medical journals was vanishingly small, in the age of Google and PubMed this is no longer the case. The casual process of disguising names may no longer offer enough protection. Clinicians must decide how to request permission to publish a patient’s case or learn to thoughtfully and systematically de-identify patients. What new elements could this introduce into the patient-doctor relationship?

Physicians write about patients in other familiar ways. Thomas Robey, in this month’s clinical pearl, looks at the humble medical record. Even the everyday activity of composing patient notes is an act of representation. A good note can communicate volumes to the next clinician who sees the patient, and how we represent a patient in the record has the power to materially shape future treatment.

Robey describes the value to students of keeping a patient journal during medical training to remind them of the patients that impacted them the most.

The narrative medicine movement in medical education places a similar emphasis on encouraging students to engage with patient stories and the roles they play within them. By guiding students to apply narrative techniques to the patient's life story, educators like Johanna Shapiro and her colleagues hope to encourage medical students' "moral imagination" and help them become empathic clinicians. Martin Kohn, his fellow educators, and students find an equally creative way to present and re-present students' stories, establishing a "reflective moral community" and helping them gain insight into their medical training experience.

Narrative medicine teaches us how storytelling can be a vehicle for ethical thinking, but what about the ethics of storytelling itself? In his commentary on this month's second clinical case Jack Coulehan addresses physician authorship of a memoir intended for a public audience. Patient confidentiality, he argues, has been a core value in medicine, embedded in Hippocratic tradition as well as in more contemporary concepts of patient autonomy and self-determination. How can physicians write and publish patient stories and still respect these ethical boundaries? In the genre of "creative nonfiction" in which many contemporary physician authors write, this is uncertain ground.

Just like physicians who publish in professional journals, popular physician-authors may also be expected to live up to a certain standard of truth. Often physician writers change, merge, or otherwise de-identify individuals, opting for "story-truth" over "what-happened truth," to borrow the distinctions of writer Tim O'Brien [2]. This can be problematic for the authorial obligation of "keeping faith with the reader" [3], unless the author "lets [the audience] in on the secret." Sometimes, however, physicians can treat in writing what they can't treat in the clinic. Patient stories as narratives of personal struggles, loss, and triumph can have enormous power. In making these stories public, physicians can harness this narrative power to raise awareness of health issues that can only be solved at a community or policy level.

In a purely nonfiction format such as journalism, expectations of truth are radically different than they are in a memoir. What in one format is perfectly appropriate storytelling license is highly problematic in another. This standard of factual truth places special demands on physicians who are also health journalists working for newspapers or media networks. In this month's policy forum, Tom Linden writes about the balance physician-journalists must achieve between two binding codes of ethics that can sometimes appear to be in conflict. On the one hand lies concern for the patient and the delicate line between the reporter-subject and doctor-patient relationships, on the other, a dedication to obtaining and disseminating factual information.

Sometimes a work that presents itself as pure fiction can make as dramatic an impact as journalistic truth. Howard Brody, in this month's medical narrative feature looks

at what has arguably been one of the most controversial novels about the medical profession, Samuel Shem's searing 1978 satire of American residency training *The House of God*. Loosely based on the author's own experience, the novel was a bestseller among residents—while infuriating attendings—and did its part to influence later reforms in residency training. How, Brody asks, has training changed in the last 30 years, and how has it stayed the same? In this month's journal discussion, Angeline Wang looks at how cardiologist John Stone evokes, through the medium of poetry, certain emotional truths of illness and doctoring that would perhaps be inaccessible in any other format.

Writing about patients is not a new enterprise. William Carlos Williams, a general physician practicing in New Jersey, became one of the leading American poets of the twentieth century; Anton Chekhov, the late nineteenth-century Russian dramatist and short story writer, also drew on his medical experience [4, 5]. In today's world, writing about patients is no longer the sole province of physicians with particular literary (and time-management) talent. Blogs by physicians, medical students, and other health professionals number in the thousands [6]. As Bryan Vartabedian, Jay Baruch, and Emily Amos point out in their commentaries on this issue's third case, many of the challenges faced by physicians communicating through blogs and other social media are unique to the immediacy and accessibility of online communications, but many are not. Considerations of confidentiality and representation are the same whether a physician publishes in a traditional print format with the benefit of an editor or self-publishes on the Internet. Physician activity on blogs and social media often brings up questions of professionalism. Just as in print media, even when physicians do not represent patients' stories, they do represent themselves and, many argue, the medical profession overall. As the commentators point out, however, the responsibility can cut both ways. Immature or injudicious comments can do damage to patients, colleagues, and the profession as a whole. However, by providing an open forum for discussion and disseminating quality medical information, physician blogs can have the opposite effect. Do physicians as a group perhaps have an obligation to expand their online presence? The increasing urgency of these questions has prompted responses from professional organizations, for example the AMA's 2011 policy on professionalism in social media, this month's opinion in "the code says" section.

Writing in the *Lancet*, Faith McClellan draws a parallel between the physician's clinical gaze and the writer's sensibility. Both, she remarks, "are engaged in an often complex process of identification with and detachment from their subjects—close enough for compassion, distanced enough for critique" [7]. In examining the ethical and practical issues intertwined in the clinician-writer's enterprise, outside perspectives can provide that critical distance. In this month's op-ed G. Thomas Couser examines the patient's perspective: even when a clinician follows all of the standard ethical guidelines, there is still a potential for "delayed iatrogenic pain" when the patient later reads about him- or herself. For this reason, Couser advocates careful moral reflection from the clinician: even when the patient gives permission, would he or she be disturbed to find his or her own story in an "alien discourse"?

In this month's medicine and society feature, Susan Sample shifts the focus from physician-writers' portrayal of patients and their vulnerabilities to how the writers portray their own. Critics and readers expect physician-authors trading in such personal and emotional capital to be likewise emotionally invested in what they write, to speak from a "threshold of vulnerability" that makes their humanity accessible to readers. Valarie Blake explores yet another perspective in the health law section. Although societal expectations encourage openness from physicians who write and publish, the legal system sometimes takes a different view.

As physician and bioethicist Edmund Pellegrino puts it, literature and medicine "are ways of looking at man and both are, at heart, moral enterprises. Both must start by seeing life bare, without averting their gaze" [8]. In this light, the confluence of writing, medicine, and ethical reflection we see from so many angles throughout this issue of *Virtual Mentor* is not at all coincidental. Only a small number of physicians have the time, talent, or inclination to write professionally, but all physicians are in some way engaged in a narrative enterprise. In small, everyday ways physicians engage in acts of representation when they share patient stories, and it is frequently through stories of patients that we perpetuate the ethical core of our profession. The advent of narrative medicine in medical education, the clinician presence in social media, and the expanding number of physician memoirs urge us to find contemporary solutions to timeless issues and remind us that we should handle the bodies and the stories of our patients with equal care.

References

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