What do all of the doctors have in common?

Besides being well-known, if they lived in our time, they would most likely be violating HIPAA by showing their patients in these pictures.

As a final-year resident in internal medicine and pediatrics, I wistfully take note that I shall probably never have a (legal) picture like theirs. In today’s world, the spontaneous act of taking a picture with one’s patient (that may be shown publicly) would violate the privacy of the patient and make the legal department nervous.

I sometimes pass the doors and bulletin boards in the patient rooms of some of my senior colleagues in pediatrics and its subspecialties. Proudly displayed there, as probably displayed on pediatricians’ doors elsewhere in this country, are pictures of babies, siblings, and proud parents. Should we ask them to take these pictures down? Perhaps there is a file of HIPAA consents somewhere in a back office.

Clearly, doctor-patient relationships and patient privacy and confidentiality issues are different today than they were in times past. However, some things have changed (HIPAA is new, for ex-

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*Albert Schweitzer and a patient*¹
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*The pediatric cardiologist Dr Hellen Taussig*²
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*The Doctor*³
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Why Do Physicians Write?
What motivates a physician to write about patients for a larger audience—the one beyond the co-providers of medical care in a hospital or clinical setting? The question is important because it can speak to the motive, sensitivity, and proclivity of the writer to appropriate or exploit his/her patient. I submit the following:

(1) Writers are prone to the same morbid fascination with tragedy and drama as the rest of us and have the same desire to talk about it. Throughout history, patients with disfiguring conditions, bizarre behavior, or terrible injuries have been the object of our curiosity. Perhaps the same irresistible pull makes us slow down to watch the scene of a car accident. Of course, civilized society teaches us from an early age to restrain our impulses. Professional codes of ethics, the Hippocratic Oath, and legal structures such as HIPAA restrain the outright violation of patient’s privacy.

(2) Of course, it is physicians’ professional responsibility to care for their patients. The outcome of a clinical encounter is always of professional significance. However, because medicine is different from other professions in that it brings the practitioner close to human suffering and death, the interest and care of the patient goes beyond mere professional interest. The alleged clinical distance notwithstanding, most physicians are moved by their patients’ situations. While most do not articulate their intentions in words, narrative writing is an effort to better understand and take in the bigger picture of their patients’ life and illness.

In an increasingly patient-centered focus in medicine, it is important to remember that the physician is not a bystander in the story but a key protagonist. In encouraging empathy in physicians as an essential attribute in good patient care, we are asking physicians to let down their emotional guard and participate emotionally in their patient’s illness. The patient’s story becomes the doctor’s story. The doctor may grieve a death or celebrate a saved life almost as a member of the family would. Does this give ownership of the experience lived to the physician as well as the patient? Sometimes physicians need to witness their own experience, perhaps as catharsis, perhaps as testimony.

The Hippocratic Oath, HIPAA, and Writing
Sensitive to the patient’s need for privacy, dignity, and protection, Hippocrates included these words in his Oath: “What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.”

The Health Insurance Portability and Accountability Act passed by the US Congress in 1996 recognized the need for rules to govern the disclosure of patient protected health information (PHI), while protecting patient rights.

Both the Hippocratic Oath and the privacy requirements of HIPAA were not developed to stifle creativity, inhibit storytelling or prevent the therapeutic catharsis of physicians. They were developed to protect the patients of these physician writers. With appropriate effort derived from a respect for the patient’s right to privacy, a well-intentioned physician writer can still find a way to tell his or her story.

It is easy to become caught up in obstacles and hurdles that HIPAA can impose on physicians trying to care for patients. Sometimes we long for a no-holds-barred environment unencumbered by rules.

Before I began residency, I read a number of books about the lives of doctors and residents. As a newer generation medical student, I was warned and cautioned by enlightened physician-authors against referring to my patient as the “gall bladder in bed 3.” Yet by the time I found my way to the wards as a clinical clerk, medicine had returned to referring to the patient as the “gall bladder in bed 3” albeit for a different reason—the protection of his or her privacy.

More than once I have been slightly irritated when a nurse’s voice on the other end of a phone, calling to ask me a question at 3 am, says something like “345 is having pain. I have given her Tyle-nol. Is there anything else we can do?” I struggle to find my sign-out sheet, deftly placed face down on my clipboard (to prevent accidental spilling of patient information when I carry it around the hospital). My sleep-deprived mind is struggling to decipher who “345” is and screams in defense: “I know all my patients, they are real people to me, not room numbers.” I sometimes ask in plaintive exasperation, “Who is 345 again?” I can almost hear the discomfort in the voice over the phone as a raspy reply, several decibels lower, tries to go against the grain of HIPPA training to pronounce a name.

Physicians who wish to use patients’ stories without obtaining written consent must “de-identify Protected Health Information.” This may take the form of removing from the narrative the 18 identifiers that can conceal the patient’s identity. Alternatively, one can create composite patient characters or modify nonessential details to fictionalize the patient. Of course, the way to tell the richest, most nuanced patient story would be with the consent and even cooperation of the patient.

In the end, even if HIPAA constrains us to publicly refer to our patient as the “gall bladder in bed
3,” it may not lead to the empathetic physician depersonalizing him or her. Whether empathy can be taught to those who seem to demonstrate a lack of it is another question altogether\(^9,10\) and one that data would suggest is unaffected by the cryptic references HIPAA may reintroduce into the health care work environment.

Medicine has always been a world of conflicting needs for physician authors—the need to write, the need for catharsis, the need to get the story out, the patient’s need for privacy, the right to own his or her story, and the need to protect it. In the end, the well-intentioned physician will do right by his or her patient. The constraints of the Hippocratic Oath and HIPAA exist for the rest.

As I began residency, I resolved to make my own small contribution to this tradition, albeit in the 21st century medium of the blog.\(^11\) But then, there is HIPAA to consider. By the time I eviscerated the 18 identifiers from my patient, I felt more like Hannibal Lector than A.J. Cronin – tricky business, this. Still, a number of medical residents and students do have blogs that chronicle their experiences and the stories of their patients.\(^12\)

It is harder to write patients’ stories in today’s more closely regulated legal environment. However, with appropriate care, the motivated physician-writer can follow in the traditions of those who have gone before. The challenges are old and new. May this generation not drop the baton in the relay of physician-writers.

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