Telling tales out of school: a look at appropriation in medical writing

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> *A silent tug-of-war over the possession of the story of illness is frequently at the heart of the tension between doctors and patients, for that tension is in part a struggle over who is to be its author and in what language, a struggle for the interpretation of life (and death) events.*
>
> Kathryn Montgomery Hunter, ***Doctors' Stories: The Narrative Structure of Medical Knowledge*** p. 13

Most of the people I've met as patients do not know I'm a writer. Take, for example, an elderly man I met on the general surgery service at the end of my third year of medical school. In St. John's from a remote part of our province, he was here to have most of his stomach removed for cancer. On the first attempt to do the surgery, he had a cardiac arrest on the operating table. They brought him back, but aborted the surgery. I met him when he was still recovering, waiting for a second attempt.

Most days, rounds were manic, with no time to really even listen to anyone describe how they slept or whether they had any pain. On this particular day, my intern had called in sick, there were no clinics to rush off to, and I wasn't needed in the operating room, so I took my time going around. I wrote notes on all the patients on our list, and then I went back to the gastrectomy patient's room. I pulled a chair up to his beside and sat.

Months before this, I had broken my back in a canoeing accident. During my own recovery, I had spoken to an old friend of my mother's, a nurse from my hometown in rural Alberta, and had confided to her a small heartbreak: in the context of narrowly escaping death, people found my worries about how I'd do my grocery shopping or walk my new dog to be rather trivial. Emilie, with her great compassion and wisdom, said to me: *We are not good at asking, 'What do you fear most?'* I vowed then to be the kind of doctor who *would* ask. And yet, out of shyness or impatience or never feeling the time was right, I had never asked anyone.

And so, on a sunny Friday morning on the general surgery ward, I asked my elderly friend, "What are you most afraid of?" What surprised me most was not his answer – that he wouldn't live to see his young granddaughter grow up – but that he hadn't miss a beat in answering. The question had been foremost in his mind, but he'd never been given an opportunity to voice it. There was a strong lesson in that for me, so I wrote and published an essay about it (Kidd, 2007).

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As Kathryn Mongtomery Hunter argues in her 1991 book *Doctors' Stories: The Narrative Structure of Medical Knowledge*, the "case" – that is, the account of one particular person's illness – forms both the basic unit of thought and discourse in medicine, and comprises a fundamental ritual. We see patients, take our notes, and then we tell the story to our colleagues like so:

> *An 83 year-old woman with a known history of diabetes and heart disease presents to emerg with a three-hour history of weakness and jaw pain. On exam, she was distressed, her blood pressure was 120/80, pulse 112, O2 sats 94% on 2L.*

And so on. Contained in that tidy story are subjective reports of weakness and pain, and if we were to continue, objective findings of congestive heart failure, the clinical diagnosis of acute coronary syndrome, and finally, the subsequent management.

As Hunter further explains, the case presentation is in fact a highly structured literary form that invites calm amid "a mind-boggling sea of detail." And so, while the case looks like a narrative, with a beginning, middle and end -- as medical students discover quickly when they leave their first two years of text-book study for the final two years of clerkship on the wards -- the case is in fact a highly distilled abstraction. It's a rare 83 year-old woman indeed who will say in one sentence that she's been feeling weak and has been having jaw pain for the past three hours. What one is much more likely to encounter is a story that wanders from, "I haven't been feeling right since my operation," to, "My friend Marge thinks it's pneumonia," and back to, "My doctor started me on a new pill. It's a little white one." This is what we could call a natural story: unrehearsed, naked of agenda. An invitation into a life. For the physician, both the case and the story end with diagnosis and treatment; for the patient, the case is merely one rise in an ever-unfolding plot.

Distilling such a natural story into a case is useful for addressing pertinent positive and negative findings efficiently in order to quickly arrive at a diagnosis and choose the most enticing management from the vast dim sum of evidence-based medicine. It's necessary to get anywhere in the run of a medical day. But creating cases from stories carries a cost: one loses the details that allow the human being to be reconstituted from the case. And who can relate to a case?

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Fast forward a few months. I am in the lobby of our main teaching hospital, and I bump into the wife and daughter of my old gastrectomy patient: he has returned for more treatment. On seeing me, his daughter reaches into her bag and lifts out copies of two of my books. "He looked you up on the Internet when he went home and found out you were a writer," she says. "I ordered these for him. Would you sign them?" Partly embarrassed, partly flattered, I do as I am asked.

It is my opportunity to tell them about the essay I published about him, but instead I hold my tongue. He would likely be flattered – he was the hero of the story, and I'd massaged

the details slightly to remove some of the uncharitable comments he'd made about some people close to him – but still I feel sheepish. Should I have asked him for his permission before publishing the essay? Truth be told, I didn't know I was going to write about him until long after he had gone home. Privacy rules at our hospital preclude us from looking up information about former patients, so officially I was not permitted to look up his number in the computer. Still, it would not have been difficult to find him in the phone book. Or perhaps on the Internet, as he had found me.

When I worked as a reporter for CBC, it was against our professional ethics to allow an interview subject to hear the final version of an interview or read the final copy of a news story before it went to air, for fear it would bias the reporter. I think that impulse copies over to my life as a medical writer: *Don't write by committee*, a voice whispers; *tell the story the best way you know how, and accept the consequences.* But a reporter does not have the same duty of care toward her subject that a medical student or doctor does toward her patient. Who am I when I write? An essayist or a doctor? Which set of rules apply? In reportage, implicit permission is granted to a reporter to use one's story when one agrees to speak to that reporter. There is no such permission granted to doctors. In fact, the opposite is true: we are bound to protect our patient's privacy except when that person is at risk of harming himself or others.

Yet I feel strongly that stories are powerful tools to shape our moral development as people and as doctors. Think of Atul Gawand's books, *Complications* and *Better*. A Harvard-trained surgeon and a staff writer for *The New Yorker*, his stories do not preach the goodness of the all-powerful physician; rather, they highlight the frailty at the centre of medicine as a human endeavour. In his books I found a compassionate man full of imagination and humility. I cried at the end of one of them. I wanted to get on a plane and fly to Boston and give him a great big hug for making me proud of medicine again. (Or at least send him an email. In the end, I did neither.) Illness stories, such as Joan Didion's *The Year of Magical Thinking* (2006), in which she recounts the year following her husband's sudden death, may humble us and help us remember that at the centre of every case is a family – sometimes celebrating, but often grieving and frightened.

Non-medical stories, too, perhaps even more powerfully, have the ability to help us see past our own skins. Consider these: Salman Rushdie makes us willing accomplices to murder with his Professor Solanka in *Fury*; Jonathan Safran Foer transforms us into a bereaved nine year-old boy in *Extremely Loud and Incredibly Close*; We become a 16 year-old young Hindu/Catholic/Muslim man shipwrecked with zoo animals through Yann Martel's *Life of Pi*. A battle rages in the medical education literature just now as to whether empathy can or cannot be taught. Perhaps empathy cannot be created from dust, but given any germ at all, can certainly be cultivated through imagination and a bit of sunlight and fresh air. These are scarce commodities in hospitals, so I say: bring on the stories.

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A few days after meeting his daughter and wife in the hospital, I decided to head upstairs and pay my old patient a visit. I went to the room number they'd given me, knocked on the door, and found someone else entirely in his bed. I excused myself and returned to the nursing station where staff told me he had died over the week-end. I had lost my chance to tell him about the essay. I had lost my chance to seek his absolution for borrowing his story.

As Adams (2008) argues, when we take a piece of someone's narrative, we inevitably decontextualize and skew it. We also get to have the last word, because our subjects – even if they are aware they *are* subjects – can rarely respond in kind, in the same format, side by side with our version of events. We, the teller, have narrative privilege.

Yet I don't regret writing the essay, or even going about it in the way I did: because it is at least as revealing about me as it is about him. His illness was my inciting incident. Obtaining informed consent to being the anonymized subject of a story stands to destroy the distance an author needs to maintain from her subject. It stands to destroy the dramatic license she may wield in the telling of her story. It stands to destroy her *authority*.

Writing a story is a little like raising a child: one does one's best to shape the thing, to teach it, to make it proud and helpful, but in the end one sends it on its way in the world and hopes for the best. One can never really know how others will receive it,whom it might harm and whom it might help. Yet both the rearing and the writing are essential to our survival. Stories teach us how to live. According to *Literature and Medicine* editor Charles Anderson (1998), stories teach medical students how to be members of a tribe, how to create and maintain identity, how to ask questions marginalized in regular medical training, such as *Who should die? What is a good death?* They help undo, in part, what sociologist Arthur Frank (1997) refers to as the medical colonialization of patients, the process that begins when a patient's chart, rather than his own lived experience, becomes the official story of his illness.

To whom does a story belong? I am torn about the answer. The doctor in me says: the one who lives it. The writer in me says: the one who tells it. Either way, we need them as much as we need oxygen, and writing them (with tact) is worth the cost of appropriation.

References

Anderson, Charles M. 1998. "Forty acres of cotton waiting to be picked": Medical Students, Storytelling, and the Rhetoric of Healing. *Literature and Medicine* 17: 280-297.

Didion, Joan. 2006. *The Year of Magical Thinking*. Vintage: New York.

Foer, Jonathan S. 2006. *Extremely Loud and Incredibly Close*. Mariner Books: Boston.

Frank, Arthur W. 1997. *The Wounded Storyteller: Body, Illness and Ethics.* University of Chicago Press: Chicago.

Gawande, Atul. 2008. *Better: A Surgeon's Notes on Performance*. Picador: New York.

Gawande, Atul. 2003. *Complications: A Surgeon's Notes on an Imperfect Science*. Picador: New York.

Hunter, Kathryn Montgomery. 1991. *Doctors' Stories: The Narrative Structure of Medical Knowledge.* Princeton University Press: Princeton.

Kidd, 2007. "What do patients fear most?" *medscape.com*, posted 09/10/2007.

Martel, Yann. 2002. *Life of Pi.* Vintage Canada: Toronto.

Rushdie, Salman. 2001. *Fury.* Vintage Canada: Toronto.