An extraordinary moment

The healing power of stories

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Medicine is a narrative art, and physicians are inveterate storytellers…physicians have always practiced the craft of narrative as a central feature of professional practice.
Donald Pollock[1]

In the name of efficiency, it is easy to block out patients' stories and deal only with the "facts," to see the chat, the time, and the stories as luxuries for when there is a cancellation. The study of narrative tells us, however, that in these easily neglected moments, we might find more than we expect; there can be understanding, relationship building, and healing—the elements of our common humanity.

In this paper, I discuss the extent to which medicine is informed and permeated by stories, explore the links between story and illness, and propose that greater attention to narrative can not only improve our medicine, but also improve our relationship with our work. I do not address the specific fields of narrative or discourse analysis, or the practice of theme extraction.[2,3] I want to talk about stories and the value of stories in our work. I will illustrate this discussion with examples of my struggle to understand, value, and learn from the stories patients have told me and conclude with suggestions for ways that we can allow stories to help us clinically and, in times of escalating demands, perhaps imbue our work with new meaning.

The place of stories in medical practice has been well documented by anthropologists and physicians alike[4]:

> Physicians talk in stories, whether discussing patients anecdotally or analyzing "cases" in formal settings such as morbidity and mortality conferences or grand rounds. They teach through stories.... Physicians practice in stories. They carry out their work by developing narrative accounts of patients and formulating therapeutic activities in relation to these anecdotes. They reason and make decisions in narrative terms.[5]

Cassell tells us that "[p]hysicians illustrate the meaning of events for each other by telling stories; in fact, medicine is awash with stories."[6] Perhaps we are overwhelmed by stories and confused by what role they should play in this era of evidence and the genome.

Story and history

Personal narratives, including those written during the course of illness, are not linear, coherent, or even logical; they are messy and written "on the fly." Medicine has a coherent linear story structure of disease that gets applied to patients in making diagnoses. Much of early medical training focuses on mastering the formulaic story of the medical history and the process of seeing patterns and diseases in the stories our patients tell us.

Our professional relationship to story begins early. One of the first clinical experiences we can have is to "take a history." We don't say that we "listen to a patient's history." We *take* the history and we make it our own, trying to turn it into symptoms and findings. We are not hearing the patient's story; we are eliciting answers, pieces of stories, to fit them into our evolving diagnosis or story template, or into one of a few possible story templates that are the differential diagnosis. We are interpreting what people tell us as we apply our medical framework to their stories.

A patient's story

I was a resident on a rural rotation, working in the clinic of a small community. It was the end of the morning, and as everyone in the clinic was leaving for lunch, I was told I had another patient. All I wanted to do was eat my lunch and get caught up on phone calls and charts from the morning. I took a deep breath and went into the examination room. I was met by a small elderly woman who had been brought in by her daughter. She was concerned that her mother, who lived alone, was "not right." Her mother had lost some weight, was quite fatigued, and was not eating.

Before I had really finished hearing the reason for the visit, alarm bells were going off. But I just wanted my morning to end, so I was trying to block out the bells and find something quick and easy. I noticed she had a thin chart. She told me she "never doctored much," and she'd lived a simple and remarkably isolated life. There were no other symptoms, and her history was otherwise non-contributory.

Recognizing that something was wrong, I set about to find what it was. From the moment I picked up the thin chart and walked into the room, I had been taking what she was telling me and what I could see and trying to write a story for her that fit a medical story outline—trying to make a diagnosis.

She was thin, cachectic, pale, and frail looking, despite her many layers of clothes. I wondered if the clothes were intentional to hide her wasted frame. I began a physical examination. Her vital signs were within normal limits; her chest was clear; her heart sounds were normal; and her abdomen was benign.

I was pretty sure she had cancer, but it was a question of where, so I had to keep looking. Knowing she had not been receiving annual or even semi-annual physicals, I hesitated to request permission to examine her breasts and do a pelvic examination, but I was confident that was where I'd find the answer. I hate doing these parts of an examination at the first visit with someone, but I was compelled to take this situation seriously. I was aware that her presence in the clinic was important, and that if she left, she might not come back. I was reluctant to invade her well-protected privacy.

The breast examination revealed a large, hard, fixed, and open mass in her left breast. I stated the obvious. "You have a mass here."

"It is where he hit me," she responded.

I explained that this mass was likely cancer and the root of her current troubles. I told her I wanted to make arrangements for her to be seen in a larger centre where she would have some investigations and the doctors would talk to her about how to approach the disease. The woman and her daughter nodded, and I excused myself to make arrangements for her to be seen at the tertiary care centre, which was an hour and a world away.

I felt as though I had done the best I could for her at the time. I was rather pleased with myself for having seen her, taken her seriously, and moved her along in the system.

I couldn't stop thinking about how it would be to have a mass like that develop. At the end of the day, I discussed it with one of the nurses at the clinic. She told me that in the past, people believed that bumping or injuring your breast would cause cancer.

This patient's history was nothing but story. But it was a story that had not been shared with her health care providers or anyone, for all I knew. Her story was one of abuse. I missed her story completely because we did not have a common story, and I made mine the dominant story. What had she really needed from me that day?

How would things be different if I were able to leave my narrative structure and move toward my patient's narrative structure? I do not mean I would throw away my stethoscope or forget my medical training; I am just wondering what would happen if I resituated myself. Could I visit the place from which the story arose and from which it was told?

Clinical interactions have been described as "transactions between explanatory models."[7] In medicine we take patients' explanations and filter them through our understanding of medicine, then give them back to them as diagnoses and management plans. "The doctor's overall aim in the clinical encounter is to subdue or settle the issue, seeking coherence. The patient's aim is to break through, seeking relief."[8] We have different goals and don't often arrive at a truly common story. Kirmayer tells us that the "mutual subversion of accounts leads to the failure to construct a shared narrative on which joint action can proceed."[8] If a shared narrative is necessary for patient and physician to proceed together, then perhaps the lack of a shared story can explain some "treatment failures" or "non-compliance," and patients "lost to follow-up."

Our stories get ill too

In *Intoxicated by My Illness,* Broyard tells us that "[t]here's a physical self who's ill, and there's a metaphysical self who's ill. When you die, your philosophy dies along with you."[9] When people become ill, their stories become ill too; the narrative structure and stability of the stories are disrupted. This has been described as a broken narrative, or a "narrative wreck."[10] Whether this is in the context of the initial presentation of a new or acute illness, or a turn in a chronic illness, there is a disruption: the person's story, as it has been projected into the future, is broken.

As I care for cancer patients and struggle to realign the numbers on laboratory reports, I wonder whether they are struggling to realign their stories. Could it be that the stories they have of their past and future, the stories they have written and read with the years of their lives have been torn from them? While I am trying to convince them of my medical understanding, are they trying to find a story that fits? "[N]arratives are part of the process of healing, when this cultural work is successful, narrative ameliorates disruption: it enables the narrator to mend the disruption by weaving it into the fabric of life, to put experience into perspective."[11] Might I do a better job if I think of patients' time in hospital as a period of narrative adjustment as a new story emerges?

> "Emergent narratives....are not the routine enactments of prior texts but are improvised as well as embodied. They are usually invented more or less on the spot, unrehearsed dramas that spring up in the course of everyday activity."[12]

> "Stories have to repair the damage that illness had done to the ill person's sense of where she is in life, and where she may be going."[10] Illness demands the creation of a new story, and the telling of the story heals the disruption and creates a future.

> "An important function of illness narratives is to integrate illness into the larger context of life...[study of] narrative reorganization of the self and social life following disruptive events found that such reconstructions often serve to create a sense of biographical continuity."[13]

What would happen if we thought of acute illness as "a situation where narratives have not yet been constructed, or where multiple tentative accounts coexist and compete"?[14]

Among the hospitalized oncology patients I encounter in my work are some who have been living with cancer for years and have had time to realign their stories. Some have just received devastating diagnoses, or are undergoing workups that will lead to devastating diagnoses. Might these people be experiencing narrative emergencies?

The goals of care in the face of advanced cancer or the end of life are often not to cure. When illness has damaged stories, let us tend to the stories to help repair some of the damage done by illness. Might we then help people to die with coherent stories, with congruence between their lived experience and their medical care? A good death is not just about symptom management, it is also about coherence. In our attempts to deliver care we must ask: What story shall we tell together?

A patient's life

An elderly gentleman, frail and failing was admitted to the oncology unit with elevated serum calcium levels. He was incoherent and incontinent. One day, after his calcium level had returned to normal, I went into his room. He was dressed and pressed and looking for things to do. He wanted to tell some stories, and I had time. He told me of working the summer shows and doing car stunts, driving on 2 wheels, experiencing near-misses, and giving the crowd a thrill; of being young and vital. He had no recollection of his acute illness, but he needed to tell me who he *really* was. It was a meaningful hour for both of us. His story became about the life he had lived and not just about his laboratory values.

Evidence and narrative

In medicine much interest and value is placed on evidence-based practice. Does this new positivism leave room for narrative? Is narrative valid in this paradigm?[15] Our medicine is disease-focused, population-based, and does little to interpret information in the context of individuals.[16] "The 'truths' established by the empirical observation of populations in randomised trials and cohort studies cannot be mechanistically applied to individual patients (whose behaviour is irremediably contextual and idiosyncratic) or episodes of illness."[16] Evidence-based medicine helps us understand populations, while narrative helps us understand individuals. We must learn to embrace the tension between these approaches and model this for medical students[3] for "genuine evidence-based practice actually presupposes an interpretive paradigm in which the patient experiences illness in a unique and contextual way."[17]

A patient's career

The first time I met Mr M, all I knew of him was that he had a spinal cord compression resulting in paraplegia and imaging suggestive of mesothelioma. His story became more complex when I learned that he had spent a career working in the insulation industry and that he had a leadership role in raising money for research on early detection of mesothelioma. He was in a room overlooking a building where his employees were removing the asbestos he had put in at the beginning of his career, without the protection they now wore. A stream of barrel-chested, wheezing friends and co-workers came to visit, and I imagined them thinking "which one of us will be next?"

Narrative medicine and possible solutions

On the one hand we have patients and narratives, and on the other, physicians and the medical record. The narrative "provides meaning, context, and perspective for [the patient's] predicament. It defines how, why, and in what way the patient is ill."[18] The same can be said of the role of medical diagnoses and records for physicians. If we see the physician's role as keeper and interpreter of medical knowledge and clinical interactions, then that role will be very different from that of an intermediary or someone who is in the space between medicine and patient—one who can access and bridge the 2 worlds, one who can see both and find a commonality and a coherence.

I don't write this from a place of mastery, but as someone who is learning. As clinicians we have a great opportunity to work in the space between the world of medicine and the world of a patient. There must be space for people to share their stories, and I must be capable of hearing them before we can begin to work together.

In that intermediate space there is tension, but there is also the opportunity to write a mutually agreeable story. Those of you have read Fadiman's *The Spirit Catches You and You Fall Down*[19] will recall the great distance between the medical diagnosis of epilepsy and the Hmong understanding represented in the title; I see her account as an example of a situation in which a mutually agreeable story remained elusive.

The metaphors of reader, writer, and text have been applied to medicine, and I think my job is to collaborate with a patient in writing a story. This is a constructivist

enterprise,[20] one that has the potential to be not only part of the diagnostic process, but also part of the healing process. "[T]he goal is to weave the narrative strands of self into tapestry, a seamless whole, or at least a cognitively and socially workable and rhetorically powerful account."[21] Something that will support us all.

I am drawn to a constructivist approach—one that sees narrative as one of the ways we seek and create meaning.[3] If I view a story with detached clinical gaze, I remain external to it; I see the story as an object and relegate the patient to "other."[22] If, however, I am able to enter into that patient's world even slightly, to be open to somehow leaving mine, then perhaps I can do what has been described as "think[ing] with stories."[3,23] "To think about a story is to reduce it to its content and then analyze that content. To think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's own life."[12]

Tending to our own stories

The scientific focus of medical education "not only fails to encourage personal development in the physician, but also invalidates much of the student's intuitive, premedical understanding of people (those who become the patients) and of their desires."[24] Medical practice does nothing to rectify this, so we might have moved so far away from our own sense of self and our own stories that we need to first heal ourselves.

"It takes a whole doctor to treat a whole patient.... In the case of a narrative-based practice of empathetic witnessing, it also takes a whole (embodied) doctor to hear the whole patient. Such 'wholeness' must involve a self-aware practice that incorporates both professional and personal realities."[25] This underlines "the physician's need to understand and be in right relationship with him/herself."[26] Family medicine has shown the way by placing the person at the centre of our work as physicians. We can be confident that we are expected to bring ourselves to our work and to care for ourselves. To do our work we must not only experience the affect and emotion of the stories, but also witness the stories we live. In doing this we recognize the humanity we share with those we seek to serve. We must honour, understand, and care for our own stories to really participate in the "collaborative effort of healing."[27]

Practical suggestions for a more narrative practice

- Recognize the storied nature of medical practice, and be aware of patients' stories as well as their histories.
- In times of crisis, think about the narrative disruption and seek to heal it too.
- Experiment with trying to construct truly mutual stories and reflect on patient interactions and clinical effect.
- Tend to your own stories, and foster the conditions for "wholeness."
- Create a culture of valuing humanism with your immediate colleagues.

Vision and hope for the future

When Broyard experienced prostate cancer, he wrote:

> [I]t doesn't take much time to make good contact, but beyond that, the emotional burden of avoiding the patient may be much harder on the doctor than he imagines. It may be this that sometimes makes him complain of feeling harassed. A doctor's job would be so much more interesting and satisfying if he simply let himself plunge into the patient, if he could lose his own fear of falling.[28]

Mattingly also suggests the benefit that narrative brings to practice:

> Coming to recognize narrative moments that arise in clinical practice may also illuminate some aspects of healing that are likely to be neglected....[T]he very possibility of healing may depend upon the capacity and desire of the actors to transform the merely ordinary into an extraordinary moment."[29]

We must help learners to value their own humanistic development as a way of placing value on the patient-centred approach.[30] Those of us in practice must place all stories and our shared humanity at the centre of our work and model how to attend to them in practice. "By bridging the divide that separates the physician from the patient, the self, colleagues, and society, narrative medicine can help physicians offer accurate, engaged, authentic, and effective care of the sick."[31] In providing excellent care, let us work with the knowledge that being diligent and up-to-date demands that we enter into the stories of others. Let us make extraordinary moments.[12]

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