

## **Narrative Medicine: An Exploration**

All the stories I've told and heard,  
most too brief and simple,  
of patients here and there--  
little bits of history,  
little stories all their own,  
how you came in with nausea and vomiting,  
how you came in with fever and chills,  
how you came in with something that never got  
diagnosed, at best we make a  
guess.  
We tell doctors some things--  
we tell these little facts.  
(These facts, which of course are not  
enough, do not contain the  
feeling, those moments when your  
illness first took  
broad strides into your  
life.)  
You dig through the medical record,  
you find the diagnosis and the dates—  
stage this of that disease,  
diagnosed how and why.  
Of all the stories I've told,  
of IV lines and radiography,  
of current medications, pending tests,  
I know there is a way to do this  
that ventures past fact  
that ventures past “pertinent medical details”  
that ventures into health  
the whole way through

Last month I was fortunate to be able to focus on the role of narratives in the practice of medicine. I am a fourth year medical student, nearing graduation. The fourth year of medical school is the only one that offers a certain number of elective months to its students; up until then, the curriculum is completely set. Fourth year

students get to pick between a number of electives, most of which are clinically based, but some of which give students a chance to emphasize other areas integral to medicine: research, teaching, etc. One of these, the elective in “narrative medicine,” gives students a chance to focus on patient’s personal stories, an unusual opportunity in an education that mostly focuses on medical facts and clinical judgment.

I myself enjoyed this experience immensely. The clinical portion of the elective is structured rather loosely: each student finds some sort of clinical preceptor who provides the student access to patients. From here, the student puts together some sort of project based on patient interview and experiences.

For my project, I chose to work with members of the child psychiatry consult service at Riley hospital, a children’s hospital in Indianapolis. The psychiatry consult team sees patients from anywhere in the hospital, as requested by the patient’s primary medical team. The consult team consists of a child psychiatrist, a clinical psychologist, a medical resident in psychiatry, a social worker, a child psychiatry nurse, and a medical student or two. Rounds are in the morning, when everyone gives updates on what has been going on with their patients, and the team might get a little information about a new patient that someone would need to interview that day. During my time with the consult service I would often hop along with whoever was doing the initial interview. Then, later, I would come back and talk to the patient (and family members if they were around), this time in a less formal setting.

There was a *lot* of narrative this month. Just as designed, the month gave me time to really consider the nature of narrative in medicine, the nature of storytelling in medicine--really, the nature of personal experience in medicine. Obviously, there is a large human element in the practice of medicine. Even if this aspect is not always uppermost in clinicians’ minds, there it is, undeniable to anyone who looks closely.

The practice of medicine involves real people, who have unique and individual feelings, experiences, and stories.

And as I thought more about it, I realized that the term “narrative medicine” can be used to encompass a large swath of the aspects of medical school that have appealed to me the most. I am a storyteller and an avid reader; I feel I understand the world best through the process of expressing and comprehending language. An English major, I also studied psychology and anthropology, religion and philosophy. Many of my interests in these subjects centered on some central themes: how do people think and how do people feel? What are they thinking and feeling, and why? I loved learning about the differences in people’s perceptions, the differences in the way they thought and viewed the world.

For me, science was a second love. I think of science as essentially the systematic study of patterns in nature; my favorite part is the study of connections between various phenomena, in essence, the story of how the world is put together. Not everyone would conceptualize the process of science in this way, but to me, the process of narrative creation is a key component of science. The narrative might be dry to those not invested in the material, but every scientific theory, every scientific paper written is composed of a certain narrative. If A then B, unless C then D or maybe E. Etc. The narrative structure remains. To really understand a phenomenon, one must be able to explain how it connects to other known phenomena in a clear and distinct way. And often in science, it is in fleshing out the “story” of a given theory that we identify the true gaps in our knowledge, the true areas where our reasoning is flawed or our questions lead to more questions. All of science depends on these theories of the world, these “stories”, that sooner or later, all turn out to connect to other stories in unexpected ways, and most of which turn out to be incomplete in

scope (if not outright false). Certain stories dominate science for a while, only to be undermined or replaced by newly emerging stories, as eventually the truth asserts itself. So goes the theory, anyway.

These are the two poles of “narrative medicine” that I love: patients’ and medical professionals’ personal experiences and perspectives, but also the underlying narrative of the science of the medicine. If we really want a full picture, we must understand both aspects and how they feed into one another. These poles overlap a fair amount; it’s only at the edges that they can be separated at all. The clinician’s judgment, of course, is determined by the way these two interweave, his understanding of the science of medicine, and his understanding of how a given patient’s symptoms correspond.

There is more to say about all of this of course, but I’d rather start by jumping into some brief narratives shaped from the time I spent with the child psychiatry team. I participated in many other patient narratives over the course of the month, but these are the ones I am choosing to share. Some are in prose, some are in a form closer to poetry, but I hope all of them display something about the nature of narrative in medicine.

## **A.P.**

One of my favorite experiences of patient narratives last month centered around a fifteen year old boy, A.P. I believe it was one of my favorite narratives for a few different reasons, including the easy likeability of the main character and the more in-depth perspective that I was able to achieve in this particular patient story. This was a patient that I was able to visit for several days in a row, seeing how the “narrative” evolved day by day. I was also fortunate to be able to talk with this patient’s mother and pastor, giving another layer of nuance and understanding to the situation.

AP was hospitalized due to some extensive burns that he had received. He was out of the ICU now, recovering on the burn unit. He had been playing with fire in a gas can when a big plume of flame had engulfed him. Apparently this was something that he liked to do, experiment with fire. This was something his mother knew, and didn’t actively discourage by her own account: this time the experiment had gotten out of hand.

Hearing this part of the story one tends to suspect, (or at least I did), “what else is going on here? Is this kid of normal intelligence? Does he have some sort of behavioral issues going on?” and maybe, “Should his mother have been supervising him more closely?”

I first got the backstory on AP from the psychiatry resident who had done the intake interview on him the day before. The psychiatry team had been consulted because A.P. had some delirium (hallucinations, probably due to painkillers). This had passed, but the kid had some anxiety surrounding the event. When he was trying to fall asleep, he would sometimes have flashbacks of being on fire, which upset him a great deal.

A.P.'s strategy was to avoid thinking about the event as much as possible. The resident actively discouraged this response, thinking it was more likely to cause him difficulty in the long run. I was reminded from my psychiatry rotation that "acute stress syndrome" could only be diagnosed after a month post traumatic incident, and that a diagnosis of "post traumatic stress disorder" required an even longer interval.

It felt like the resident was intent on diagnosing him with SOMETHING anyway. I have so much respect for psychiatrists and the work they do. They certainly have the opportunity to approach the personal side of medicine with a greater depth than most general medicine doctors—by definition, they are supposed to put more time and emphasis on feelings, thoughts, perceptions. And yet I feel like there is something sort of impersonal in the typical approach of the psychiatrist, not that I am sure that this is necessarily a bad thing. There is a certain professionalism maintained, a certain distance.

There is also, I feel, a certain urge to propel patients into categories. I feel like this is partly a result of psychiatry trying to imitate general medicine, with its more objective categorizations. Diastolic congestive heart failure stage II is different from diastolic congestive heart failure stage III in some very important and easily verifiable ways. For myself, I'm not sure it makes sense to set up psychiatry in the same way. Aren't disturbances of the self and spirit a little more malleable, a little more idiosyncratic? But as soon as we characterize these matters as medical mental illness, we start thinking along different lines. These are obviously big questions, too big to really address here, but ultimately these questions do shape the ongoing "narrative" in different ways. Narrative is partly shaped by the beliefs and concepts of those in the narrative. For example, psychiatrists are trained in a certain way of thinking about psychiatric illness; though they definitely consider the social and

psychological aspects of patients, ultimately they tend to conceptualize patients in terms of the psychiatric categorizations that have been set up by their profession. Lay people don't necessarily view the world this way, which I'm sure is ultimately part of the distrust of the psychiatric professionals which is still present among a large part of the general public.

I was able to chat with A.P.'s mother on a couple of occasions. She told me about what a "good kid" her son was, making mostly As and Bs, never getting into trouble, always pleasant, "except he was stupid enough to do this." She had a poor opinion of psychiatrists from her personal experience, and she told me she was confident her son didn't have "that kind of problem." "There's nothing really wrong with him . . . that way." She seemed to open up to me a little after she realized I just wanted to chat with her and wasn't trying to do an official psychiatric evaluation. It was just the two of them at home, and she thought they got along fairly well, though he was kind of a quiet kid. The family's youth pastor, who I talked to briefly, seconded this assessment, saying that he found it difficult to get A.P. to open up while in a group of kids unless you asked exactly the right questions.

I could see what they meant. He did seem quiet and a little self-conscious, but after a while I began to find subjects that interested him: his dog, the Beatles, science fiction. (We had a rather longish discussion of this in which I recommended Ursula LeGuin, the only sci-fi writer I know well.) He played in the high school band, and was missing his friends there after spending a couple of weeks in the hospital. I wanted to tell him it would be all right. He wasn't asking me, but I wanted to tell him. I felt like I was more worried than he was about how other people might react to his burn scars—at least he wasn't showing that worry. Other than not wanting to think about the fire, he seemed to be doing pretty well, I thought. All the cards and calls he had

received after the fire had made him feel like he really did have friends that cared about him—it had meant something to his self-esteem to see that.

The last afternoon I chatted with A.P. he was nervous about his upcoming departure from the hospital. His mother was sort of horrified by the dressing changes that he needed for the new skin grafts on his forearms, and had said that she couldn't handle helping with that. A.P. was doing fine with this himself, but I could tell he was a little overwhelmed with the prospect of leaving the support of the hospital environment. A health aide would be coming to help out with that for a while, but it felt like it was about more than that. Of course it was. We talked a little about it, but not much. I wished him well, hoping he would be one of those people who maintain a positive attitude in a negative situation, taking every opportunity to learn and grow from it. A.P. was definitely a quiet kid, but I felt he had some inner resources he could draw upon in the weeks and months ahead.

**A.W.**

“pseudo-seizure, pseudo-self”

we think you didn't really have a  
seizure, though yes, you shook and fell.

It's dubious to tell you this I feel.

After all, it is not as simple as

knowledge leading to cure—

it is not at all about faking.

It is about something else, entirely.

It is about this whatever world  
attached too much to your mind.

It is about pain and fear

riding through you, and

too much of it, and

a little fragment, wandering lonely,

peels off, fakes out,

demands its own, wanting

more than you can give it—

wanting, something else.

“Just a version of dissociation, a  
disruption in the self, a hole.”

Psychogenic

Non-epileptic

Seizure—

This weird event,

whose origin is obscure

“you lack the true signs of seizure,

your EEG betrays you and the

way you closed your eyes.

It lasted too long and the way you

moved your head was

wrong.”

I don't know what to tell you, kid.

I get it—(I get it some . . . )

How whatever stress

has burrowed its way in, and

outs itself, in time.

Dissociation is borrowed time,

at best.

**D.W.**

I am at a loss to convey the sprawling narratives of D.W., a 19 year-old patient with sickle cell disease. D. W. loved to talk, telling me about all his problems with little prompting. He said he was a “pretty chill” guy who liked to take things in stride—when he could. He’d quit school a couple of years before graduating due to his frequent sickle cell crises: now he didn’t have a job, a G.E.D., or much in the way of prospects at the moment, though he said that he really wanted to work and hated just hanging around with TV and video games all day. He told me about his “love/hate relationship” with his mom, who had just recently moved back in with him and his grandmother. He told me about his “sort of a girlfriend”, how his mom didn’t like her, etc. He told me his mother thought he was addicted to pain pills, but he wasn’t. His relationship with his dad was “tense”; he had accused D.W. of selling his medications. There was more I won’t get into here, but he managed to convey a fair bit of drama about his personal life.

D.W. was stuck in the hospital for a sickle cell crisis, which can occur when the patient’s genetically malformed red blood cells obstruct tiny blood vessels and restrict blood flow to organs, leading to pain. His physicians were having a hard time getting the crisis under control—he had already been in the hospital a couple of weeks when I met him. He was upset that he’d been in the hospital so long; he’d missed two birthdays and a funeral. The psychiatry consult team had been called for “pain, coping skills, and stress reduction.” The resident did some guided imagery and deep breathing exercises, and he seemed to respond positively to these. But obviously none of this removed the immediate source of pain or stress.

He complained to me most that “people treat me like a kid because I’m sick.” I could see what he meant by that—I think it’s a challenge faced by many young people with chronic illness. Yet you had a sense that this was only half of the story—if

people treated him like a kid, he partly liked it. You felt like he was very comfortable with the special allowances his disease had given him. He seemed somewhat ambivalent about this growing up thing, too, which likely would present special challenges to him, as a person with a chronic medical illness. He seemed to want the freedom of the adult world without the corresponding responsibilities.

I watched a little as the psychiatry resident tried to point this out to him. It was hard to tell if she was making any real progress with this aspect—he was fairly quiet as she sort of lectured him about it. Sometimes it is hard to see things about ourselves until we are ready to see them, even when they are pointed out to us by someone else—perhaps especially when they are pointed out to us by someone else. And of course this is only one perspective; I'm sure DW's personal narrative differs, as would be expected.

**M.E.**

“ulcerative colitis status post proctocolectomy and jpouch and loop ileostomy”

I take a moment to talk to talk to you--  
brown hair, soft eyes, an eager smile.  
I am eager to tell you a little about your procedure.  
(Like this surgery has really solved what's most  
Important in your life.)  
There is no way to tell that.  
The soul, untouched of course,  
still intact, still with this  
brazen attitude of  
good times to be born.  
So instead, I listen a little,  
as you tell me about what is  
Right with you—  
your loves, your hopes—  
with eyes that have learned a  
patience, a looking-forward,  
that I never could.  
Tell me what you know.

**S. L.**

Another patient I talked with, Miss S. L., was a seventeen-year-old girl who had been hanging out in the hospital for a couple of days when I met her. S. had been diagnosed with type I diabetes a year and a half ago, and recently her blood sugars had been totally out of control. Unlike type I diabetes, this form of diabetes is caused by the autoimmune destruction of certain cells in the pancreas that are responsible for insulin production. Insulin plays multiple roles in cellular metabolism, but one of its most important roles is the uptake of glucose from the bloodstream into cells after a meal. Without it, the level of glucose in the blood, the “blood sugar,” can skyrocket, causing multiple symptoms. It can be a difficult disease for patients to manage, as they have to give themselves life-long doses of insulin to replace the insulin that is not being made by the pancreas. The insulin doses have to be calculated individually for a given meal, and it can be easy to overshoot or undershoot the dose, especially early on in the management of the disease. Both excessively high and excessively low insulin levels can lead to medical emergencies, and in the long term, excessively low insulin can lead to damage in multiple organ systems.

Miss L. was being hospitalized for management of her blood sugar level. As it turned out, these were NOT out of control when she was taking her insulin and other medications as prescribed, and it was implied in the medical notes that perhaps she was not taking her medicine at home quite as regularly and carefully as she said she did. Hence the psych consults. The psychiatry team was seeing her for “mood and psychological component to a medical condition”. Talking with her, and thinking about things later, I had a chance to reflect on how often mood and psychological factors contribute to a medical condition. Sometimes this is more direct than other times, of course, and sometimes the contribution is more significant, but to me it seems these factors often strongly influence health conditions, in ways we don’t

always bother to look at clearly. In S's case, the contribution seemed fairly direct, and so her medical team asked for a psychiatry consult to help deal with the messy personal stuff.

S. had had kind of a rough year. First she had received her diabetes diagnosis, which required strict attention to her diet as well as carefully regimented insulin shots. She'd had a lot of abdominal pain over the past year, chronic headaches—both at this point attributed to psychological causes. She also complained of fatigue, and hadn't been able to play much on her high school volleyball team. She had missed quite a bit of school for all this, and her grades had plummeted. It sucked, it all sucked as far as she was concerned—she had not signed up for this diabetes thing, and it was proving to be more than a huge inconvenience. Her friends just did not get it, she explained to me—peers and even teachers were giving her advice on what she needed to do to manage her diabetes, but it seemed to be based on their experience of type II diabetes, and in many cases it was simply incorrect. Her “friends” accused her of faking her symptoms: “they think it's my fault . . . that I'm sick.” S. admitted to me that her parents' recent divorce was also stressing her out as well, though we didn't discuss this in any detail.

It was hard for me to imagine what it must be like for S. to adapt to all of this successfully. I had a feeling she might be angry about the diagnosis, angry about having to change her life around for it, angry that it seemed to take up so much time and effort, angry that her friends weren't sympathetic enough, just . . . angry, though actually her manner and demeanor were fairly subdued. She was more irritable than she used to be, she told me, more moody. I wanted to tell her that her life would rearrange itself, that she would find ways to adapt, but I knew she would be skeptical—it hadn't happened yet, and she'd had this diagnosis for well over a year.

## **E.C.**

One of the latter patients I met with proved to be the most personally challenging of the interviews I performed. Though I thought about why this was, I didn't come to any concrete conclusions. E.C. had been diagnosed with borderline personality disorder, a condition with which I had some familiarity through a close friendship. At a certain point this friendship exploded rather dramatically in ways I didn't really understand at the time, though I knew theoretically that this person had this "borderline" diagnosis. I'm sure this past experience had something to do with my strong reaction to E.C.'s story, but I feel there must have been other factors at play as well.

E.C. had obtained her diagnosis of borderline personality disorder several years previously. I think it can be a trap to stick psychiatric labels on individuals too quickly, especially as it increases the chances that we will focus too much on diagnostic categories at the expense of the individual. That said, E.C. had fairly obtained the described characteristics of this particular pattern of illness, including a suicide attempt on a previous occasion. With borderline personality disorder, long-term patterns of unstable and turbulent emotions, poor self-image, and impulsive actions are the norm, and relationships tend to be chaotic: an alternative term for the syndrome is emotionally unstable personality disorder. Dissociative states and self injury are also not uncommon. Many have experienced some sort of trauma and have endured difficult psychosocial situations. That said, psychiatrists and other mental health professionals are still debating how best to characterize this particular group of patients.

E.C. had landed in the hospital because of a suicide attempt, ingestion of multiple types of pills. We talked to her about what had been going on prior to that.

In a detached monotone, she told us that no, she had not thought about the safety plan she had previously set up with her psychiatrist. She didn't seem upset or sad talking about this at all—it was as if she were describing someone else's life. She denied feeling depressed, denied feeling hopeless or worthless, and she couldn't or wouldn't provide any context for the suicide attempt. "I just wasn't thinking about it," she volunteered. Mostly she mentioned that she was tired. Then she briefly mentioned that a couple of days before this she had just remembered a time when her mother had sexually molested her when she was a young child. Her mother often did cocaine, she said, and had been busy with this during E.C.'s ingestion: "she refused to take me to the hospital." According to E.C., child protective services did make occasional visits, but her mother always "lied her way . . . through the meetings". Her mother had denied all of this, and seemed particularly upset about the sexual molestation "memory".

It was hard to know what to make of any of this. Was this truly a recovered memory or was it some sort of fabrication? I was glad it wasn't my job to sort it all through: it seemed like a mess, one way or another.

I did a mini-writing exercise with E.C. She had expressed an interest in English, and I thought she might get something out of it. I just asked her some questions about how she was feeling and what she wanted, and wrote her responses down for her. Here is what we came up with:

I'm tired.  
I'm tired of being tired.  
I want to take a nap.  
I want to take a nap.  
I want to not be tired.  
I love my sister.  
I love to do things with her.  
I feel bored.  
I want to go home.

As we went through this, she began to show some flickers of emotion, in contrast to the detached, dissociated attitude she had displayed up until then.

I don't have a good idea as to how things will turn out for E.C. In the short term, she was going to be hospitalized at Methodist hospital as a psychiatry patient. She clearly did not want to do this, but she was a minor and didn't have any choice in the matter. More broadly I wondered how she would do, how her life would go from here. She wanted to go to college, she wanted to leave home; she wanted to study to become a mortician, of all things. I hoped that her life would become more stable, both externally and internally. I hoped that she would be able to find some therapy which would work for her. I've heard some good things about dialectical behavior therapy with patients with borderline personality disorder, which uses some techniques of mindful awareness coupled with cognitive-behavioral techniques. But this type of therapy requires a form of moderately intense intervention and is not available at every facility. Many patients diagnosed with borderline personality disorder do not do well, even with the best therapy can offer, but I decided I would try and be hopeful for her, when I remembered her in the days ahead. You never really know who is going to turn things around, in medicine or in life: it's best to keep alive hope where we can.

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