

Murmurs: Stories from Our Journey in Medicine
[Season 2, Episode 2: Check Engine Light](#)
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Podcast Transcript

Speakers

Qiuwei Yang, Jesse Sardell, Heather Finlay-Morreale, Hugh Silk

Hugh Silk 00:21

Welcome back to the podcast Murmurs: Stories from Our Journey in Medicine. This podcast series is meant to act as reflective experience for the way health providers and those in training think about their patients in medicine, not so much about how they make diagnoses, but about how they relate to their patients, continue to think about them long after a visit, and what makes doctors and nurses tick. Each episode, we will interview someone from UMass Medical School who has written a creative piece and listen to the story behind it. The hope is that this podcast will inspire others to be more reflective practitioners as well.

Qiuwei Yang 00:54

And this is Qiuwei.

Jesse Sardell 00:56

And this is Jesse.

Qiuwei Yang 00:57

And we're excited to introduce our guest Dr. Heather Finlay-Morreale.

Jesse Sardell 01:02

Dr. Heather Finlay-Morreale is a pediatrician and former Doximity writing fellow. Many of her works chronicle her experiences as a patient with a chronic disease, navigating the healthcare world as both a physician and a patient. And her essays have been featured in Kevin MD, Doximity, and JAMA journals, among others. Today, Dr. Finlay-Morreale will be sharing her piece "Check Engine Light." Before we ask you to read, could you tell us a bit about what led you to write it?

Heather Finlay-Morreale 01:32

Ever since I was even a teenager, I kind of write to process things. So if something that happened to me, or something I read is kind of stirring up ideas or stirring up emotions, I can kind of draft responses in my head of what I might want to say. And it can even kind of keep me up at night, if I'm just thinking over something. And so I write to kind of process things and get things to quiet down and you know, get out of my head, you know, put it on the page. And there it is. I often you know, compose an idea or an outline or even, you know, striking certain sentences or images, mentally. And actually I used to commute to Sterling, which is kind of a semi country commute. And so this piece, I actually kind of thought the idea of and drafted a good part of it in my head on the way into work. And then I typed out

the whole piece at lunch. And I actually did very, very few edits. And then I got accepted to the journal, you know, within a day. So, you know, this piece is a little different from some of the others in how much flow there was creating it. So this piece is called Check Engine Light, it was published in JAMA Neurology. And here it goes. I bought a new car a year ago, my first new car. Like many purchasers, safety features were a big consideration, and one feature of this car is that the front passenger seat has a sensor for weight, and if it detects a person in the front passenger seat that weighs under 60 lbs, it shuts off the airbag so that the child sitting in the seat doesn't get injured by the airbag. So shortly after I got the car, there was an adult passenger in the seat and the light came on showing that the front airbag was lit up and that the front airbag would not deploy. So I brought it to the dealer, and by then the light was acting normally and was fine. And no one at the dealer had ever heard of this problem. So they kind of just believed it. And then nothing showed up on any of the diagnostics that they ran. So they decided there was no problem. And they sent me home. So I was at a work conference on Cape Cod. And it happened again. And this time, my husband googled it and found other people who had had the same problem. And he reached under the seat and was jiggling and wiggling and there's a wire under there. And then the airbag came back on and the light turned off. The wire under the seat that wiggles seems like a particularly poor design feature. I went back to the dealer and once again, they couldn't replicate the issue and nothing showed up on the diagnostics. And once again, I was sent home. Again, no one at the dealer had ever heard of this problem occurring to other drivers, despite there being a number of complaints found online by my husband without much searching. So it happened again, at this point, it was the fourth time that I brought it back. And I really insisted, you know, you've got to fix this once and for all, you know, I can't keep coming back for this. And you know, this was the airbag for goodness sakes that was not functioning, it needs to work. So they replaced the seat cushion and that jiggling wire thing, etc. And the problem didn't occur to me, it didn't occur again. So, this week, when I wrote the essay, I received a letter from the manufacturer, that there was a recall for that exact issue that I had brought to their attention. So the exact same and serious issue that when I brought it to their attention they dismissed me and ignored me and sent me away. So the same week that I got the letter about the car recall, I learned the final diagnosis for a health issue that I've been having for decades. And my experience with the check engine light is very similar to my diagnosis, diagnosis experience in several ways. So first, my symptoms, akin to an airbag malfunction, were severe and alarming. They included widespread severe pain, occipital, trigeminal and post herpetic neuralgia, severe fatigue, chronic intractable migraines, and autonomic dysfunction. And, you know, in my whole life, I, you know, I've probably seen 50 doctors if you include specialists and PCPs, etc. And similar to the car passing all of its diagnostics, all my lab tests and MRIs were normal, my exam was essentially normal. And that's a common experience to many patients with chronic pain, pain is subjective and not always measurable. And neuralgia doesn't usually show up on MRIs despite being really serious and really impacting people's lives. So many physicians just dismissed me. One ER doctor saw me unable to walk due to so much pain in my torso. Despite ketorolac and other medications they'd given me there, my CT was normal. So they told me to go home and take ibuprofen. They never gave me an exam. They certainly never gave me a diagnosis. And once the CT was negative, there was no further workup. And if this is how I was treated, you know, a white physician, you can imagine how people with less societal privilege are treated in similar situations. So like my car, the doctor thought that you know, all the diagnostics were normal, so there's not a problem. I'd also been told over the years that my issues were from stress of being a resident or anxiety or unresolved trauma, or my favorite, which is that the symptoms were entirely imaginary. So, like my husband and I

did with the car, when we received a lack of understanding from the dealer, I went online. So I joined several online patient groups for people with similar issues and found that my experiences are not unique. Without fail, those of us with chronic pain are told it's due to stress or anxiety or depression, or attention seeking etc, etc. So, untreated pain that is ignored again and again by medical professionals, and limiting life activities, can make someone stressed or sad or anxious. And, you know, like many people with a chronic rare multi-system illness, I saw many providers who were unable to come up with a unifying diagnosis for all of my different issues. So the better physicians that I saw admitted I did probably have some, you know, overarching disorder explaining everything or most everything. The worst ones just saw a set of symptoms that they couldn't explain and assumed it was psychosomatic or suggested they were not real. And there is nothing more maddening and demeaning than being told that your lived authentic experience is not real. So the online forums actually, were a great source of solace, and also community. So you know, like others online, I kind of crowdsourced my symptoms and my experiences and got some really useful tips and advice. And then crowdsourcing in these communities and some other kind of leads I picked up in different places actually led me to find out what my own likely diagnosis was, and then seek out a knowledgeable physician to confirm. I actually got led to a YouTube video lecture by this particular physician to a patient group. And you know, once I watched that video, I was like, Yep, that's it. So I saw that exact doctor, and a biopsy confirmed that I have something called small fiber neuropathy, which affects sensory pain nerves, specifically autonomic nerves. And it is diagnosed by very few doctors, even in the medical mecca of Massachusetts. Probably less than five do the biopsy that I know of, and it is also treated by relatively few doctors even in this area. So my experiences both as a patient, and then in my own medical training has shown me that there's a systemic way that rigorous medical training and the hidden curriculum invalidates patient's subjective experiences. And patients are harmed by this practice, both emotionally and you know, clinically or medically. And it's a set of blinders on physicians that impedes the ability to diagnose people and treat people. And at the same time, there's people with functional disorders, and you have to tell the difference between, you know, functional disorders and a rare disorder, or an unusual presentation of a common disorder and that can be difficult. In my own practice, the last time I diagnosed a patient with a functional disorder, I was wrong. So and that was the last time I did that, so I may have swung too far on the dial. But I'm now extremely unlikely to diagnose a patient with a functional or psychosomatic disorder unless I've thoroughly worked them up, carefully evaluated all the clinical evidence, looked up, you know, aspects of their presentation and resources, consulting colleagues, and so on. And actually, this last paragraph, and specifically, the use of the word functional, was not in my original essay, the editor told me I had to talk about functional disorders in the essay to get it accepted, or you know, as part of the review process, so I actually don't use the word functional. So you know, after this point, after getting a diagnosis, it's a whole new experience. It's an explanation for what was going on, I really felt vindicated and validated, I was relieved. So you know, I wasn't thrilled to have a severe disease. But at least now I had a path. There is a treatment, and I was able to find a doctor who prescribes that treatment, and my check engine light is finally off.

Qiuwei Yang 11:01

Thank you so much for sharing. I think your piece is particularly powerful, especially since seeing patients for myself, sometimes the biggest question they have is just what's going on with me, like, give me a name to my symptoms, so that I can keep going from here.

Heather Finlay-Morreale 11:17

Yeah, exactly. Not knowing the name is really frustrating and difficult. It's also makes it impossible for people to access resources. There are people equally as sick as I am. But they don't have a diagnosis because they are not able to access the kind of medical resources that I am. And they are, you know, unable to work but also unable to get disability, unable to get Social Security, unable to get work accommodations, until you have a diagnosis. All of this is shut off from you.

Jesse Sardell 11:48

In your work, you indicate that part of the hidden curriculum of medicine involves the attribution of chronic pain to stress or psychiatric diagnoses. Could you talk a bit about whether you had to unlearn a hidden curriculum during your own journey with chronic pain?

Heather Finlay-Morreale 12:06

Yeah, I actually had to unlearn both the hidden curriculum and the overt curriculum, especially regarding pain. The issues with opioids has changed the discussion of pain in medical schools. And I found really, a lot of what I learned was not true. I mean, just as one example, you know, you're taught to memorize that opioids and NSAIDs do not help neuropathic pain, that's actually not true. For some people, that helps quite a bit. There's a lot of variation and individuality in people. And it's also true that not everybody who uses, desires, or even gets withdrawal from opioid use has a substance use disorder. So yeah, so there's both a hidden and an overt curriculum, particularly around pain, that's problematic. And then it seems like at the start of third year, you know, everyone gets their little pocket card that lists you know, antibiotic dosing, or lab values, etc. And it really seems like people are also given a list of people to distrust: people with substance use, women, black people, people with bipolar, or schizophrenia, people who are dramatic. And I mean, it really starts from day one of third year. You know, so that's another aspect that's kind of infuriating to me. And that was, that was always infuriating to me. And part of the hidden curriculum is that, you know, the doctor mentality of just push harder, just try harder, don't be weak, you know, don't go in sick ever, you know, hook up an IV and go to work when you have sepsis. I mean, it's crazy, this attitude. So part of this attitude, you know, got ingrained in me. I kind of produced something that people called internalized ableism, which is, you know, it was hard for me to even believe that I was sick, and that I wasn't just faking it, and that I shouldn't just push harder. And, and I have a lot of symptoms, that initially seemed really weird. And when I would hear them in my head, I'd be like, Wow, that's really weird. That can't be real. And I would edit myself when I would go to doctors, and it actually kind of impeded the diagnostic process. And then when I have the diagnosis, and I look up, you know, the symptoms people have with it. I'm like, oh, that is real. It's not just weird talk. So, yeah, there's a lot but the hardest thing I think, is always doubting myself and just thinking I should just try harder, and forge ahead.

Qiuwei Yang 14:35

Yeah, it sounds like the hidden curriculum and the overt curriculum and medical school is a lot of, I guess, mistrust of certain populations, as well as this hammering down of what it means to be a physician. Like, in some ways, it seems like to be a physician is to inherently be an able-bodied person, which is not true. And so I think that's a really, really good point. And I think one specific line from your narrative, quote, "There's nothing more maddening and demeaning than being told that your lived authentic experience is not real" struck me a lot in particular, I think it's so so true. Yet sometimes when

I'm in the physician's office, and I'm on the other side of the table, I find myself kind of playing the skeptic and trying to tease apart, like, what are the symptoms? And what is colored by the patient's own perspective? Could you talk a bit about how your own approach to patients has changed over time?

Heather Finlay-Morreale 15:39

Yeah, yeah. And of course, you know, physicians being skeptics is something that maddens me. So, you know, my language may not always be PG for this answer. But even the word choice that you used after a third year, is problematic, because you say, tease apart the symptoms, and what is colored by the patient's perspective. It's the same thing, the patient's perspective of their symptoms is what is happening to them. There's nothing you need to tease apart, there's nothing different that you need to believe from what the patient tells you is going on. That's the reality. And I really think, you know, clinicians should never be the skeptic in the room, that's not your job. You know, do patients go to somebody for help? And expect them to be a skeptic? No, they go there for help, because they're having a problem. And it's not your job to decide whether people have an agenda behind what they're saying. You know, that may be different in certain select situations. You know, if you're a forensic evaluator, seeing patients who want to, you know, claim an insanity defense, that's a different situation, but, you know, normal routine clinical situations. I don't think that is what you need to do. And when patients don't wake up, skip work and family life and spend six hours in a waiting room to talk to a doctor who's a skeptic, they have no alternative. That's it.

Qiuwei Yang 17:04

You're definitely right, in the sense that it is important for physicians to believe in patients. And that you're right, that the patient's perspective, is also their symptoms, there's not really nothing to tease apart. I think for me, when I'm in the exam room, I don't know if this is the right way to go about it. But when a patient says, Oh, I have diarrhea, I guess my my meaning behind teasing apart is just okay, like, tell me like how much diarrhea do you have? Like, tell me like what the volume is? Because in some ways, the medical definitions of what is classified as like diarrhea, or what is classified as like, XYZ, may be different from the patient's perception of what's happening to their body. And so I guess, how do you like navigate that space between the medical definitions have been established, and understanding that this is definitely like a change in a patient's own baseline that they want addressed, that may not fit the medical definitions that have been put in place?

Heather Finlay-Morreale 18:14

Yeah, yeah. So it's important to examine what you mean by medical definition standards and diagnostic criteria. So you know, these don't just, you know, appear from the heavens, they are created. And who creates these standard definitions? They're created by establishment academic professors, who are still largely white men who work at referral centers and see mostly referrals of referrals. That's not the general population of people with a particular disorder. And a lot of these criteria are designed for research studies, have a uniform population to test a drug or an intervention. They're not necessarily what describes most clinical people with that problem. And you know, these people that decide what a disorder is, you know, they're the same people that are UpToDate editors, you know, something can not be in UpToDate and still be real. And this, you know, adherence to the standards as the only source of truth is really harmful. And specifically, people that are excluded from medical decision making are excluded from these committees. Their voices are not heard.

Qiuwei Yang 19:20

I think those are really, really truthful points. I think that there's a lot of people that have been excluded in medicine historically. And the standards that are established now have been defined by a population that does not look like a general population, and hopefully does not look like what physicians look like in the future. I guess my like, I guess, navigating through like medicine and like this new medical career, is there a way to move about this system in a way that's more inclusive to the general population and to patients? Because sometimes it feels like there is a standard, and we're all just trying to, like reach that quote unquote standard.

Heather Finlay-Morreale 20:06

Yeah, so I've kind of formulated, you know, as I've gone along, how to, you know, have an approach that helps patients. And interestingly, it also helps physicians to kind of avoid burnout. But, you know, it's kind of like a five step plan. And I kind of unofficially call it, you know, how not to be a doctor. So, the first step, I think, which is to is to like wipe the slate, clear your mind before you enter the room. Some people call it like a mindful moment at the door, whatever you do, but clean your mind and walk into the room fresh and curious. Unfortunately, I see from both students all the way up to attendings, you know, they read the main issue, I don't use the word complaint, but read the main issue in the chart, surf the chart a little bit, and then decide at the moment before they even walk in the door, that the issue is crap, or the person is faking, or it's a waste of time and resources, and they should not be in that medical setting. I have had a doctor walk into my room. Before they looked at me, before they talked to me, before they knew anything from me at all about that day and say, she was not going to help my problem, and I had to go home and solve it myself. Before even hearing what the problem was. And it is obvious to patients when you walk in the room. And you're not going to believe anything they say and you've already made a decision. And it's really a sign of burnout. And unfortunately, you know, I see this in third years, they already have this attitude, they're already burnt out. And you know, this toxicity starts at the top and then trickles all the way through. So when you enter an encounter with blinders on, you miss things, and you can kill someone. So I think the first step is wipe the slate and clean your mind. Sure, you can surf the chart first, it's helpful. But you know, don't have any preconceived decisions about the outcome based on that. I think the next step is to listen, start with an open ended question, you know, what's troubling you the most today? Or how can I help you today, and then let the patient talk without interruption until they stop. Almost all patients stop in one to one and a half minutes, you can give a patient one minute to talk about why they're there. You know, I think doctors have this fear, you know, got to interrupt, gotta direct things, you know, just give people a minute. And you know, be curious about what they're going to say. It really helps. And just taking those two steps, greatly helps patient care. And it also helps caregiver wellness, if you approach each encounter with open curiosity, rather than skepticism, and, you know, being tired and annoyed that you even have to talk to them. I mean, that totally changes your whole entire day. And then the third step is believe what the patient says, what they say, is real. And step four, think, all capital letters, think about their symptoms, look things up, ask smart people questions, how can you have things make sense, you know, just think about it for a minute before you make a decision. And then kind of the last step is help the patient. And it seems ludicrous that I even have to mention helping the patient is part of why you're there. But a lot of medical encounters end with no help being given whatsoever. You know, if you can't diagnose them, you may be able to treat their problem or manage their symptoms. If you can't do either of those, you

can at least be sympathetic and admit that you know what's going on with them is beyond the limits of your knowledge, or even beyond the knowledge of what is currently known in medicine, and refer them to someone smarter, don't just shut the door to further investigation. You know, I think a lot of doctors are arrogant, you know, and that if I don't know the diagnosis, then nobody does. And, you know, tell the patient to stop looking. And that's total garbage. So, you know, wipe the slate, listen, believe the patient, think, and help. It seems simple. But that doesn't get taught that that's your job. And that's your job.

Qiuwei Yang 24:23

I think we can all definitely take this into like future patient encounters as well. And then last question I have is sometimes when I'm in the office, I kind of like really cringe when a patient begins a sentence with, oh, I looked online and found, I think in part because there is a lot of misinformation out there. The online forums that you found lead to community advice and ultimately a diagnosis. So I wanted to ask what do you think is important for physicians to recognize and understand about these online forums?

Heather Finlay-Morreale 24:56

Yeah, so it's interesting. I did some googling on googling diagnoses. And there's a pile of opinion pieces by doctors all saying terrible, opinion pieces by doctors are almost all negative about googling. Patient reports of googling, there's tons of positive reports, I diagnosed several of my own issues. And I've diagnosed patients' issues by googling. So if you look at academic pieces, pieces where doctors actually look at the data, googling helps patients, and it helps doctors. There's nothing wrong with googling. So, you know, one, one aspect is that a community is found online and you can learn about other symptoms. So I had this one weird symptom where on my legs, it would feel like a bug bit me, and there would be no bug there. And that started like 15-20 years ago, and I didn't tell anybody because it sounds totally nuts. And then it got worse until it was like a pinpoint electrical zap on my legs. And I still didn't really bring it up. And it turns out, that's actually a feature of, you know, like foot neuropathy and leg neuropathy, specifically, the kind that I have. So, you know, I learned, oh, that's, you know, a real thing that's part of this, it's not, you know, just this bizarre thing. So, you know, talking to other people that have the same issue as you can be really helpful. And, you know, true, there is some garbage advice on some of these forums and advice that's harmful. There's often a moderator who polices, you know, people giving medical advice on forums like these. So, you know, a lot of them are, are moderated in some point. And people only go to these forums when for help when the doctor fails them, or they don't have health care access. And then the other thing is, you know, this is the information age, and has been for a long time. But now the information is free. It's full text, it's on the internet, it's accessible. I think, five, six years ago, 85% of Massachusetts, you know, had smartphone or computer access to the internet. So knowledge is increasingly open and free. And you know, you google how to fix your fridge and you google, you know, how to give your cat a pill. I mean, we google everything. So doctors saying don't google things is doctors trying to control and limit what information people get. That is completely patriarchal and anachronistic. Doctors should not limit what patients see about their own bodies. That's ridiculous. And if doctors don't like what's out there, you know, that's in their knowledge base. And, you know, they think certain certain things are, you know, harmful to people, well, then contact the editor and submit a new piece, it's actually relatively easy to submit pieces to get published online. It's not hard at all. So yeah, I think google is really helpful. I would say all of the most useful lay public oriented resources are free. So it used to be e-medicine for doctors. And

now there's Medscape and WebMD for patients. And patients can read both, you know, if you know, they have knowledge of the medical words, they can read the doctor version. So that's great. The Mayo Clinic has great information that's free. The NIH has great information, National Organization for Rare Diseases, Cleveland Clinic, Boston Children's, you know, professional organizations. I just actually found a good website this week from the American College of Radiology, written for patients, written for patients, specifically listing how much radiation is in each kind of study. And you know, how it relates to how much radiation you get just in life. So there's actually really great free resources for people to get information. And I do kind of see there is a, there is an issue where, you know, patients might hear about zebras that really fit their symptom. And I think there's a concern about that. And I just wanted to add that, you know, zebras exist, there are zebras. And, you know, I think I was told like three weeks ago, you know, Oh, you don't have that, you know, that that's very rare. And, and I do, so, zebras are real. And, you know, people with Addison's disease, which every single doctor gets asked about on every single board exam for the rest of their life, takes on average four to five years to get diagnosed. People suffer for four to five years. I did diagnose somebody with Addison's and they have been to two emergency rooms and discharged extremely ill and nearly unable to stand and they were sent home both times. By the time they go back from my office back to the ER they were completely unable to stand and we're approaching or in Addisonian crisis which can be fatal. The average time for autoimmune diseases, lupus, MS, etc. to get diagnosed is about eight years. Vestibular disorders, which are really disabling but have a lot of symptoms that sound weird, 10 years. So, you know, every zebra has a laundry list of doctors telling them that it can't be this because that's rare. And there's one this one doctor like on Twitter who said, you know, you're supposed to focus on horses and not think zebras, you know, but zebras do exist. And sometimes while you're thinking about the horses and zebras, you know, a lion comes down and jumps on your head. Like, there's a lot more in the world than the common everyday stuff. And I mean, I think that's what residency gives you is determining sick from, you know, not sick, and rare for more common or, you know, an uncommon type of a certain disease that you still see every so often. So, yeah, I'm in this practice that really helps you.

Qiuwei Yang 30:35

Thank you so much for your time. I think that this conversation was really productive, and I think very educational for us as well.

Heather Finlay-Morreale 30:42

Great. Thanks. Nice to be here.

Qiuwei Yang 30:44

Thanks for tuning into this episode of Murmurs: Stories from Our Journey in Medicine. If you have any questions, comments or suggestions, reach out to us via email at murmursumassmed@gmail.com. This season was produced and edited by Divya Bhatia, Qiuwei Yang, Jesse Sardell, and Lael Ngangmeni with advice from Hugh Silk. Special thanks to Jake Paulson for our original theme music and Hillary Mullan for our logo art. To learn more about medical humanities at UMass Chan, visit the Humanities Lab page on the UMass Chan Medical Library website at https://libraryguides.umassmed.edu/Humanities_lab. We'll see you soon in the next episode. Until then, keep reflecting and storytelling.