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Episode 5: Penal Code

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Murmurs: Stories from Our Journey in Medicine <u>Episode 5: Penal Code</u> 2020-07-16

Podcast Transcript

Speakers

Hugh Silk, Qiuwei Yang, Lisa Gussak, Divya Bhatia

Hugh Silk 00:21

Welcome back to the podcast Murmurs: Stories from Our Journey in Medicine. This podcast series is meant to act as a 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 01:02

The following podcast was recorded on November 2019. A lot has happened since then, including COVID-19 and the Black Lives Matter protests, which is why these particular issues were not addressed in this interview at the time of recording. We would like to acknowledge two things. First, the disproportionate impact COVID-19 has had on black, brown and American Indian communities. And second, the undeniable role that incarceration plays in perpetuating systemic racism against black, brown and indigenous communities in the United States. We call upon medical professionals to educate themselves and work towards greater equity for all of their patients, particularly their patients of color.

Hugh Silk 01:44

I'm Hugh Silk, a family physician in the Department of Family Medicine and Community Health at UMass Medical School. And I am here with my co interviewer, who I'll have introduce herself.

Qiuwei Yang 01:57

Hi, my name is Qiuwei. I'm a medical student here at UMass.

Hugh Silk 02:00

And we're also here with our guest writer today, Lisa Gussak, a family physician in the Department of Family Medicine and Community Health at UMass Medical School.

Lisa Gussak 02:09

Good to be here. Thanks so much.

Hugh Silk 02:11

Thanks for coming today, Lisa. I think we want to start off with just a general question before we get into the essay you're going to read for us. So how did you get into writing as a physician?

Lisa Gussak 02:22

Well, I found myself, oftentimes after seeing patients that I was close with or had a more significant connection with, I just would find myself thinking about them after hours. And I felt that by writing down their stories and my experience of our relationship, it kind of helped me to keep it closer to my heart and to inform my practice.

Hugh Silk 02:47

Yeah, I found one of the things that's happened since we started with the electronic health record is there's not much story in that. And so I find myself also wanting to write something to really get to what happened with the patient that's not anywhere in the electronic health record.

Lisa Gussak 03:02 Here, here.

Hugh Silk 03:03

But I understand that you have some other interests in medical humanities as well.

Lisa Gussak 03:07

Yes, I do a great deal of photography and use that as a creative outlet to keep myself grounded and passionate about what I'm doing. And I don't focus on imagery that is directly related to my medical work, but oftentimes, I do find that there are connections.

Hugh Silk 03:26 Yeah, I mean, I've seen some of your photography and I'm just blown away by it.

Lisa Gussak 03:31

Thank you.

Hugh Silk 03:31

And I understand that you do the majority of it with just using like your iPhone.

Lisa Gussak 03:35

Right. Long ago, someone said to me, You use the camera you have, and that's the one I always have with me. I actually took a street photography course and swapped with a guy in the class and he let me carry his Nikon heavy camera, about three and a half pounds, and I found that after 20 minutes of walking around with it, I was quite happy to get my phone back.

Hugh Silk 03:57

Cool. So do you think that your focus on writing and taking photos and what have you, affects your caring for patients or the way that you do your doctoring?

Lisa Gussak 04:08

Oh, absolutely. I find that putting some energy toward a creative outlet brings me back to a more centered place when I'm with patients. Because I'm, like many positions, I do find myself struggling to some degree with the amount of administrative work that we're involved in. And that caring for patients is harder given the multitude of other tasks we have. And so by keeping myself sort of focused on a different part of my brain, it gets me back in touch with what I believe is the reason I went into medicine, which is to be with people and share stories.

Hugh Silk 04:46

Yeah, I couldn't agree more as a fellow family physician, someone asked me, What are the one or two traits you have to have? And I said, Well, you have to have curiosity, and you have to have creativity. And I think when you do these things on the side, it does it just bleeds back into what you do on a day to day basis.

Lisa Gussak 05:02 Absolutely.

Hugh Silk 05:03

Right. Well, you know, we asked you to come here to read your essay. So I think what we'll do is we're going to try something different. Today we're going to have you read the first half of your essay, and then we'll pause and ask a few more questions. And we'll have you finish up. Lisa is going to read her essay called Penal Code and it was first published in Pulse: Voices from the Heart of Medicine.

Lisa Gussak 05:22 Thanks so much.

When I see Rosa's name on my patient list, I smile. I have known her nearly eight years. Under my care, she's given birth to her last two children, and although she takes the kids to a pediatrician rather than me, we have an uncanny habit of bumping into each other outside the office. I've seen her and the kids in the market, at a park and in the hospital lobby, and I have been invited to, but could not attend, a family birthday party.

Today she's coming in for a routine physical. I last saw her fourteen months ago. She needs a Pap, a follow-up on her sometimes elevated blood pressure, and paperwork documenting her vaccinations so that she can volunteer at her kids' school.

Three years ago, after the birth of her last child, she developed preeclampsia, with stubborn and difficult-to-control high blood pressure. She went on meds, but hated them and adopted the gym as her primary treatment strategy. She went nearly every day, lost twenty-five pounds in six months and came off her medications.

She's Dominican, here for many years without papers, and has never risked leaving the US to go visit her family. When her brother in the Dominican Republic was killed, she missed the funeral. Thanks to Skype, most of her family knows her kids. She's been with the same partner for longer than I've known her. She and Edwin have three kids. She has never worked outside of their home, instead focusing on raising the kids while he provides the family's financial support.

I examine her, do her Pap and fill out the required paperwork for school. Only while filling out the form do I notice the increase in her weight and blood pressure.

"Rosa, have you been checking your blood pressure and weight when you go to the gym?" I ask.

She pauses, then says, "Doctora, I haven't been to the gym in a long time." She pauses again, then says, "Money is very tight, because Edwin has been locked up for more than year."

Shocked, and wanting to make sure I heard her correctly, I repeat in Spanish what she's just told me.

"Si doctora, esta en prision," she says.

This is when you sit back down, resisting the urge to check your list to see how many other patients are waiting, and you close the computer.

Over the next fifteen minutes, she tells me that Edwin's been in prison in Concord for nearly a year on a drug-related charge.

"He has one year left, maybe less," she says. "I believe he is innocent."

I say nothing.

"Edwin's father is helping me out with money when possible, but it's a struggle," she goes on. "My gym membership stopped months ago. I'm not working. Even though I'm afraid to drive to Concord, I have friends who help me to get there nearly every week."

"How are the kids doing?" I ask.

"Only our oldest, Julia, who's nine, knows the truth about where Daddy is. I've only taken her to Concord a few times. Julia has a teacher who helped me find a support group for her, and now she knows other kids at school whose fathers are in prison."

I nod, and she keeps talking.

"I have no idea how to talk with our younger ones, who are five and three, about their dad, and they aren't asking."

"Are you interested in meeting with a counselor?" I ask.

She shakes her head. "I've got lots of friends and family to talk with, and they help me a lot."

I hug her tight before she leaves, clutching a plan for self-care, blood-pressure monitoring and a followup visit in two months.

Hugh Silk 09:04

Wow, that was great. Thanks. Thanks for sharing that, Lisa. So why did you choose to write with that patient?

Lisa Gussak 09:10

Well, my experience with her that day was just lingering in my mind, which was probably the most immediate reason. But I also just it was so palpable, her struggle. And I was very surprised that that was this patient's struggle, that I had had a sense of her as a member of a relatively stable family, actually quite stable. And so to see that her life had been so completely up ended really caught me off guard. And I found it just was not leaving my head. And I've learned over the years that if something is lingering in my head that I should write it down.

Qiuwei Yang 09:50

It also sounds like in some ways, you kind of assume that this patient was in a stable relationship. And I know so in medical school, we're taught a lot in our training to not assume things, but I feel like sometimes it's only human for you after you've established a long term rapport with this patient to be like, oh, like, this is what her life is like. And then you forget those random little changes that happen in life that take your life completely on a different course that you never thought would happen.

Lisa Gussak 10:16

Oh, I agree with that completely. And this was not a course I would have mapped out for this patient at all. And I think the the good provider, the physician that's actually connected with their patients is trying to hold both of those things in their head, both their sense of the history and the relationship and the possibility that that like every human being their life can take unusual turns and to sort of create space for that in the room. So I was actually very honored that she chose to share this with me, because I suppose it would have gone another way and maybe I didn't ask the right question on that particular day and it didn't come up and then it would have just kind of kept a whole chapter of her life closed.

Hugh Silk 10:58

Were you able that day to keep kind of a poker face and not look like you were shocked?

Lisa Gussak 11:05

I hope so. I guess I, you know, the fact that she kept talking with me about it was a sign to me that it was going okay, and that I was remaining sort of present enough for her to share with without judgment. But I do think that we, we are certainly only human. And it's possible that, you know, sometimes patients say things that really do shock us or that we laugh, maybe at the wrong moment. But I am sure I didn't laugh that day.

Hugh Silk 11:35

No, I understand that. So you're going to read the second half of your story in a second. And without giving too much away, you start to focus on some diagnostic codes. And the electronic health record

kind of plays into that a little bit. And I wonder why you chose to go down that pathway for the second half of the story.

Lisa Gussak 11:54

Well, I guess like the first half of the story, it was so shocking to me, that my effort to, to kind of document what I had learned about my patient, and which was something that I knew was going to have really a great impact on her health and well being, and the well being of her family, really was so difficult. And I just was, it was just right up in my face, you know, is immediately present in my, in my face this sort of battle that we are in with our electronic record and our, our storytelling to get back to the beginning of our interview with, you know, wanting to tell a story about a patient and make sure we tell others who follow us that same story or leave something in the record and it was just so difficult. And and it's a very clear example of sort of social determinants of health, which are so present in our care.

Hugh Silk 12:50

So things like diagnostic codes or electronic health records or boxes checking can make us cynical, and I don't know if you have a message for students and young physicians about how not to go down that pathway.

Lisa Gussak 13:06

Well, I don't know if I'd call it a message, I would tell you that my strategy is to continue to try and take away from the encounter what is sort of the most connecting part of the experience of being with a patient, which in this case is the story and is always the story. And also to remember what we said at the beginning that reflecting on that, this part of your care that fills you up, is very helpful. That coding in the boxes are not that part of medicine for me. So I think that trying to balance it in some way. And and frankly, I also do many things outside of caring for patients, which I think is very helpful. So I'm not really drowning in that part of medicine.

Hugh Silk 13:54

No, I think that's right, taking care of yourself, being in the moment in the room. Ron Epstein in his book Attending says that like when you put your hand on the doorknob, just go in there and be there. Don't worry about the codes. Don't worry about billing. And then you know, that'll come afterwards. And so well, I feel like we're, we're talking about the second half of your essay. But I think folks probably want to hear it, so why don't we have you read the conclusion?

Lisa Gussak 14:22

Great. Thanks so much.

Later that afternoon, putting together my notes in the electronic medical record, I know that I want to add something to Rosa's problem list to help myself and other caregivers remember this "problem" she is living with and trying to manage.

I plug "PRISON" into the EMR search bar and find the following:

Kitchen in prison as place of occurrence of external cause (Y92.140).

Or if the occurrence happened in the prison dining room (Y92.141) or in the swimming pool (Y92.146), if the prison has one.

Finally if you have no idea where the occurrence occurred, you can choose unspecified place (Y92.149).

Plugging in the word "INCARCERATED" yields:

Incarcerated avulsion fracture of medial epicondyle of R humerus with nonunion S42.447K

I pause and wonder how a piece of bone normally attached to the upper arm bone can become both fractured and incarcerated (the medical term for being confined or abnormally retained, a condition that prevents healing).

Incarcerated epigastric hernia K43.6.

Images of stomach tissue trapped up in the chest flash before my eyes.

Incarcerated femoral hernia K41.30.

Ditto, but this time in the groin.

...and many more variations. When I use the word "JAIL," only one option pops up:

Fever, jail A75.0

Increasingly frustrated, I try "INCARCERATED FAMILY" and get no results.

When I give it my last shot with FAMILY MEMBER IN PRISON, my EMR asks in bright blue caps if I mean "FAMILY MEMBER IMPRISONMENT," below which I'm offered:

Imprisonment of family member Z63.32

After many years of caring for underserved patients, I've learned of the enormous toll that incarceration imposes on patients and their families. The financial, social and educational costs to families often affect many generations. Mass incarceration is a public-health crisis in our country, overwhelmingly impacting men and women of color. We imprison more of our own citizens than any other country in the world.

So why is it so hard to find any acknowledgment of this cost in our modern system of medical-care documentation? And why is "FAMILY MEMBER IMPRISONMENT " a Z code? As many doctors know, and as even my EMR reminds me: "Z codes may not be reimbursed if used as a primary code."

Why should we as a society care more about the complications associated with incarcerated tissues and bones than about those associated with incarcerated people-the members of our own society we

lock up and confine in such extraordinary numbers? And why should we as a society pay doctors more to care for tissues and bones than to care for people and families who are dealing with real-life imprisonment and its impact?

I add "FAMILY MEMBER IMPRISONMENT" to Rosa's problem list, but not as a primary diagnosis.

I want to be sure my health center will get paid for the care we are providing Rosa and her family.

I know that she, Edwin and their kids will suffer the cost for a long time. I need to be sure that we'll be around to continue caring for all of them as they struggle through life's challenges, forever changed.

Qiuwei Yang 18:40

Thank you so much for sharing your Penal Code writing with us.

Lisa Gussak 18:43

You're welcome. My pleasure.

Qiuwei Yang 18:45

I have one last question actually. So as a medical student, I haven't worked extensively with the electronic health record. So could you just explain it that what Z codes are, as it seems that these codes are a very specific focus for the second half of your story.

Lisa Gussak 18:59

Coding is a system of determining the value of various diagnoses and is determined by really the entire Medicare system. And it is, I don't understand the history of why Z codes are not reimbursed, but Z codes are felt to be less important. Often, they're preventive codes, they cover all the cancer screening diagnoses, well child care, preventive health issues. And so it's felt that my take one of my takeaways is that whenever I see a Z code, I have decided that the people who are paying think that these are less important aspects of care. And in any electronic record, we'll tell you that if you put them in as the primary billing diagnosis, you're running the risk of actually not getting paid. Just kind of ironic because I do a pap smear. It's a Z code, and I may not get paid for that, but I certainly would get paid for taking care of the cervical cancer that might be diagnosed if the pap smear isn't done.

Hugh Silk 19:56

Well, as someone who worked in correctional health for years, clearly taking care of people who have been imprisoned and also their families is incredibly important. So thanks for writing that and thanks for reading today.

Lisa Gussak 20:09

You're welcome, my pleasure.

Divya Bhatia 20:20

Thanks for tuning in to this episode of our podcast 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 podcast was produced and edited by Divya Bhatia and Qiuwei Yang, with advice from Hugh Silk. Special things to Jake Paulson for our original theme music and Hillary Mullan for our logo art. To learn more about medical humanities and narrative medicine at the University of Massachusetts Medical School, visit the Humanities Lab page on the UMass Med Library website. We'll see you again soon at the next episode of Murmurs. Until then, keep reflecting and storytelling.