DocsWithDisabilities Podcast #2

Dr. Erene Stergiopolous

Part 1 of 3 Transcript

Participants: Lisa Meeks, PhD, host

Erene Stergiopoulos, MD, interviewee

Introduction: Lisa Meeks

Doctors with disabilities exist in small, but measurable numbers. How did they navigate their journey? What were the challenges? What are the benefits to patients and to their peers? What can we learn from their experiences? My name is Lisa Meeks and I am thrilled to bring you the *Docs with Disabilities* podcast.

Join me as I interview Docs, Nurses, Psychologists, OT's, PT's, Pharmacists, Dentists, and the list goes on. I'll also be interviewing the researchers and policy makers that ensure medicine remains an equal opportunity profession.

Lisa:

Today I embark on a winding, and revealing conversation with our guest Dr. Erene Stergiopoulos, a Psychiatry resident and researcher at the University of Toronto. In this vibrant city we meet up for a very real conversation about wellness and disability in medicine.

In this three-part series we discuss everything from the unwritten curriculum and mixed messages in the medical education to licensure and consequences of disclosing a psychological disability.

In part one we discuss Dr. Stergiopoulos research on the unwritten curriculum, discourse around wellness and being a good patient. We also discuss the unintended financial, social and academic consequences of leaves of absence.

Lisa:

We're in Toronto and it's so lovely to be here, although it's not very lovely

outside. It's very overcast. But I'm excited because I've never been to the

city and I was so excited to be able to interview you in person. I've been a

fan from afar and so I know we have a big future together. Can you, for the audience, introduce yourself and tell us a little bit about your background

Erene:

So my name is Erene Stergiopoulos, I just finished medical school at the

University of Toronto. I'm heading into residency, a couple of months in psychiatry, also at the University of Toronto. And I also do some research in the area of accessibility in medicine, in medical training. And I also do a little bit of student activism as well, kind of based on that research.

Lisa:

Great. I know you had a paper that came out, I want to say 2018 academic medicine [1].

Why don't you tell us a little bit about your research?

Erene:

Sure. So, the people that I work with on this research are my supervisor, Athina Martimianakis and Dr. Fernando Oshan who's an anthropologist. And the research that we did was about the experiences of Canadian medical students with disabilities using both interviews as well as kind of policy analysis, critical discourse analysis of blogs, policies, where we looked at basically the hidden curriculum around accessibility and wellness in medical school.

So what do we mean by the hidden curriculum? It's really looking at what students are learning about medicine, about what it is to be a doctor, about what it is to be a patient, but outside of what's actually on lecture slides formally in their medical school. So we think about the language the practices the policies that shape how and what students learn.

So our research was looking at not only what are medical students experiencing but also what are some of the barriers to getting access to accommodations, but also what

are some of the messages around the appropriateness of even having a disability in medicine and how does that get communicated through various institutional documents, various student discourses of how they perceive the ideal medical student to be and how they perceive that student to perform.

We found that looking at both the interview data from students as well as the textual analysis data of all these policies and documents in student affairs websites, there was

this really strong discourse of this ideal medical student, someone who doesn't really ask for help, they're performing at an extremely high level, they're doing a million different projects outside of their academics. So they're doing research, they're also really engaged socially. And they're also someone who doesn't get sick and if they do get sick, they still come into work every day. So that was something that we saw that was really not super surprising but very striking to see it so plainly laid out. And a second part of what we found was this discourse of the good patient. So this was something that came out a lot through our interviews where students talked about experiences, either witnessing patients and how they were treated when they were in their student role or seeing how they themselves were treated.

For example, this idea of the good patient with someone who was supposed to take really good care of their health. They were supposed to be really independent in managing all of their needs, taking responsibility for self-care. And so what we saw was that being a good patient and a good student was very, very hard to do at the same time. Students were kind of pulled in completely opposite directions where on one hand they're supposed to be extremely high performing and not need help. And then on the other hand, as someone with a disability or someone who is a patient, they need to completely self-manage and spend all of their time on self- management, which kind of precludes the ability to do well in school. We saw this as this really conflicting message that students were receiving where they're kind of not able to fulfill both roles.

Another part of our analysis had to do with looking at discourses of wellness because of the services that are provided to these students often fall under the mantle of resilience and wellness. And what we saw was that often wellness was actually framed as a means to achieve that ideal medical students' status. Sometimes wellness was, a means to achieve balance, a means to avoid burnout. But in a lot of cases, wellness was actually something where students and administrators and institutions mobilized it as this means to become more efficient in their studies. So it's like go to this meditation or go to this yoga lunchtime session so that you can become more efficient at work or more efficient than your studies. There were other times where it was framed as a way to get better grades.

So seeing the ways in which wellness is framed becomes this way of excluding people because it says, if you can't perform these very conspicuous self-care activities, like drinking a green smoothie or doing yoga at lunch, you're not actually performing wellness properly. So you think about students with disabilities who might not, you might need to spend a lot of their self-care time doing very different types of activities. What does that say to them? Are they appropriate for medicine if they can't perform those roles?

Lisa:

It sounds like you have to be perfect already to engage in wellness and if there's actually

any component that is unwell, you are not even a candidate to engage in the programs that exist because you might not have time. Like you said, that critical self-care. People might be attending a physician's appointment or doing physical therapy or meditating, and if they're not doing what's prescribed as wellness by the institution then they're not that stellar student.

I know today's topic, we're really going to focus on barriers what barriers you have identified in[1] the undergraduate space and what barriers do you predict going into the GME space. And how are those different when there's still a level of patient responsibility that wasn't there before. And I think that where things start to get muddied both for the individual with a disability and the disability professional or access specialist who’s trying to help them navigate these the unwritten curriculum as you like to say.

Erene:

I think that a lot of the barriers especially the ones that are not as intuitive have to do

with an absence of a communication or an absence of information around where access lives or where that contact point for inclusion can happen. For example, transitioning from undergraduate medicine to graduate medicine. I don't think that there are actually any systems in place where someone's accommodations in their undergraduate can just get forwarded to their graduate program. And what would that look like?

I think about, for example, when someone is welcomed by their program director for the first time in GME, is there a part of that email that says, "If you require accommodations, here's the one specific person to email, not a general email, not like grad dot program." So, you know, how does that message come across? And is there a space on their

website, for example, that says if you are a graduate here's how to get accommodations? Here's the HR person at the hospital where you're working that you can work with.

Lisa:

I'm so glad you brought up the generic email, I have to say that I find it to be really a [2]

microaggression of sorts. It's what's behind the curtain and were not going to tell and we're not going to tell you the processes or policies but if you feel the need to disclose, here's the single address and you don't know who it goes to you would restrict the amount of information you would share, but it can be really intimidating.

Erene:

Absolutely. I had to email a generic email when I first applied for accommodations.

Lisa:

Really?

Erene:

Yeah. It was actually a really interesting experience looking back because, there was no

publicly available information on the website of my school on how to apply or who to call or email so as a learner that the message that comes across through that is, "Oh, I must be the only person who needs an accommodation." Which is extremely isolating and othering because you feel, "Okay, I'm alone in this." And that is definitely a hidden curriculum moment, right? it's an unintended effect of a policy, or just a lack of information where a school might be very committed to equity, diversity inclusion and access for all students. But by virtue of just not having that information transparent and visible in a place that's really accessible, they've actually excluded a lot of people.

So that's definitely a barrier and I think that going into GME it becomes an even more of a barrier because programs are a lot less hands on than at the UME level. I think that an office like GME or I think here in Canada, or at least at my school, they call it PGME. So postgraduate medical education. It's not as clear what role they have in ensuring our

wellness because then there's also resident wellness committees, there's hospital-based sites and there's also like the resident union or the resident's association that also is kind of contributing to things like duty hour restrictions, or they're advocating for residents about duty hour restrictions and things like that.

It becomes just a way more complex issue because they're also getting paid there's also that pressure of, "Oh, I shouldn't take time off because of my disability because that's going to reduce the call pool and now my colleagues are going to have to take on more call. "

Lisa:

Right. One of the things that we found in our data collection[2] was that people were

reticent to initiate any type of leave or even minimal like release from overnight call, because they knew the burden would then be distributed to their peers, that in and of itself wasn't surprising because people are very altruistic and they care about other people so it makes sense that this would translate to their peer residents. What was surprising was that they said because I know that this other resident is on the fringe of a breakdown and if by my taking care of myself through leaving for appointments or attending to my sleep hygiene so that I am the healthiest person I can be to attend to my patients that I know it's going to possibly be the straw that broke the camel's back for my colleague. They were not only having to attend to their wellbeing, they were feeling very responsible for everyone's wellbeing and reporting that the actual state of wellbeing was really unknown to the program directors, that there was a lot of put on a happy face and were all doing great when in reality behind the scenes everyone was having days where they felt this may be the day where there's one too many things on my plate.

Erene:

Absolutely. And it's hard because there's all of this invisible communication between

residents where some of the people have disclosed to their program that they have a disability that they require accommodations, but just like you were saying, if you know that your colleague hasn't applied because of stigma, because of the fact that it might be something new for them and this is crisis that's just starting. How do you manage that? There's this sort of guilt when you know that everyone has it really tough and maybe this is part of medicine, like the culture of medicine, you don't want to be... the person who requires the most resources. You don't want to be needy and that's something that actually came through in your paper, in the journal of general internal medicine it was about mixed messages [3], especially that residents have to face in

training where their programs are super gung ho about wellness and resilience and taking care of yourself. But the reality of being a resident is that you have these incredibly difficult hours, you feel really really responsible for patient care because most residency programs are service based rather than really training based and residents are rewarded for self- sacrifice whether that's you know uh implicit or explicit.

There are cases where students or residents are incentivized to take more call, which is super tricky because who is that actually excluding and who doesn't have access to that incentive? Because they have a child at home or they have a disability.

Lisa:

And who is going to get the fellowship.?

Erene:

Right. It’s the person who who did one of three call instead of one and four.

Lisa:

It's a little mind-blowing kind of the hamster wheel, and I think in my practice where I saw a

medical students the fear almost focuses on not wanting to get off the wheel, because everything in motion stays in motion right? But the minute we stop, I think there was a very is real fear that it will all come flooding in and the moment of breakdown will be at that moment. So as long as we stay on the wheel everything is going to be okay because we know the wheel, we know the motion, we know[3] the body becomes acclimated to it.

Erene:

I think what you mentioned about getting off the wheel, like taking leaves of absence is

something that's still really stigmatized I think partly because you lose touch with that main support system, which is your class. So I took a little bit of extra time in my clerkship because I had a chronic physical condition where I was in a clinical trial and we had to do a lot of appointments and was managing that at the same time as doing clinic. I took an extra year and I am graduating with the class one year after my original graduating class. I have to say I loved it. I really liked being able to extend my clerkship,

it was so much better for my health. I was able to manage things and have control over my learning in a way that I don't think I would have.

Lisa:

Did you decompress your clerkship or did you opt out of blocks and come back in?

Erene:

I opted out of blocks and came back in so it was one rotation on one off.

Lisa:

So you did decompress, just in a block format?

Erene:

It was really great. The breaks in between my rotations were times where I was lucky my health was good so I was able to do research, I was able to stay productive and feel like I was still meaningfully in medical school. I think the fear is that a lot of people who face a leave of absence or who are recommended to take a leave of absence in particular...

Lisa:

We're going to come recommended in quotes. Because our listeners cannot see the

looks on our face when we talk about recommended leaves of absence.

Erene:

Yes. When students face the idea of actually pulling out of the curriculum for a given

amount of time. There is a lot of pressure to understand “What, what am I going to do for this amount of time? Who am I going to hang out with? Everyone is going to keep on going and I’m going to be left behind. And also quite pragmatically what happens with my fees? Do I have to pay extra tuition?

Lisa:

There’s so many consequences, and even the tuition, which I normally don't talk about

that's institution dependent, I've had institutions that do not charge tuition in those interims, they only charged for when you're in the clerkship. They may charge a second year of fees, which is still an impact financially but nowhere near a 40, 50, $60,000 impact. The litany of consequences that people don't think about and these consequences are pretty significant.

You mentioned the financial consequence you know other financial consequences are that so often times the student is living, that is their income, so in the absence of that they have no income whatsoever. And usually if you're taking a leave of absence, you can't work. I know that right now Dr. Joe Murray and I are on a little bit of a soapbox about medical schools ensuring that students opt into disability insurance to cover any gaps that may occur. Ideally we’d like to just them pay for all of the student's disability insurance. We think it's that important and it's relatively inexpensive for the institution. Do you want to talk about some of the other unintended consequences because there's so many?

Erene:

I think that in some cases when people take a leave of absence, if they are not given the

choice to pay their annual fees to the university, they can't use the gym anymore or they can't use the wellness services at their school. So for example, if they're seeing a personal counselor at their school, that suddenly gets cut off which is huge. I mean that is completely antithetical to the point of taking that leave for wellness. That’s completely antithetical to the point of taking that leave for wellness.

Lisa:

For the typical student who takes a leave of absence, they're gone for a chunk of time.

What are the consequences socially when that occurs?

Erene:

I think for a lot of students it's really hard to get back on the horse so to speak.

Depending on whether you're with your original class or with a new class, there's so much onus placed on the student to self-disclose all the time because people ask why were you gone? What happened? Or who are you, I've never seen you before? If you're with a new class and then you have to, basically you have a script in your head of every time you have to like explain essentially, okay, how much information am I going to disclose? How well do I know this person, Am I going to know this person for more than one day? Or am I going to be with them in clerkship for the rest of the next six months?

So I think that that's something that is completely mediated through just student interactions like accessibility services doesn't have any place in our social lives... And yet, this is part of managing accommodations. It's that not just the self-disclosure to faculty, to program directors to preceptors, it's also to our peers. Especially when disability is still very stigmatized and people think, "Oh, well it's not fair. Why don't you have to do a full-time clerkship?" So there's all of this navigation of this really, really, really complex emotional territory in an environment that's still very competitive, where people might see someone who's getting accommodations as an unfair advantage, rather than something that's actually just leveling the playing field for them.

Lisa:

It almost is exponential; the consequences and we don't think about them. It's enough

for anyone of them right: the loss of insurance, the loss of provider, the loss of finances. If you are out for 6 months all the sudden you have to start paying your loan back. So double that financial implication. But then you start adding in the social consequences and curricular consequences. Because we haven't even talked about the consequences of having to explain this upstream to GME and all of these things are sitting out there in the landscape and

they're not additive, they're exponential. And I see so often that these things are what keep people on the hamster wheel and make it a really unhealthy environment to be in.

Join us in part 2 of this critical conversation where we continue the conversation where our focus shifts to licensure, perceptions, and barriers within category of disability, professional identity as a doctor with a disability and boundaries with faculty preceptors.

References:

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