TPWKY - Special Episode - Alexandra Sifferlin

EW: [00:00:00] Hi, I'm Erin Welsh and this is, this podcast will Kill you. You are listening to the latest episode in the T-P-W-K-Y Book Club series. This is the series where I get to chat with authors of popular science and medicine books about their latest work and ask them a bunch of questions about what inspires them, what lessons we can learn, and what the future might hold.

We've covered some incredibly wide ranging topics. There's truly something for everyone out there. If you'd like to take a look at all of the books we've featured in the past, as well as get a sneak peek into the books that will be. Featuring in upcoming episodes, head over to our website. This podcast will kill you.com.

There under the extras tab, you'll find a link to our bookshop.org affiliate page. Clicking on that, we'll get you to a bunch of T-P-W-K-Y related book lists, including one for this book club. And one for the kids book club, which Aaron Updyke posts on our socials. So if you're not already following us there, you should be.

I am always updating these lists, so be sure to check in regularly if you have book suggestions, topic suggestions, a firsthand account or anything else you'd like to share. The best way to get in touch is through the Contact us form on our website or through the firsthand account form. Two last things before I can introduce this week's book, and that is to please rate, review, and subscribe.

It's a big help. And finally, you can now find full videos of most of our newest episodes on YouTube. Make sure you're subscribed to the exactly right YouTube channel, so you never miss a new episode Drop. Every year, millions of people will make an appointment with their doctor to try to make sense of a set of symptoms they're experiencing.

What happens next can fall into several different categories. Number one, they are given the correct diagnosis or start on a path that will lead to the correct diagnosis. Number two, they're given the wrong diagnosis or number three, they get no diagnosis at all despite needing one. Most of us experience the first option.

After all, we are taught that science and medicine have the answers, so of course, that's where we turn when we have questions about our health. But for

millions of people, that initial visit does not result in a correct diagnosis, nor does the second or the third. In fact, many people wait years for an answer years marked by the emotional and physical pain that comes with being considered unexplainable in the eyes of medicine.

The vast extent and profound impact of this issue has been understudied, but this week's book seeks to correct that oversight in the elusive body, doctors, patients, and the diagnosis crisis. Author and health journalist Alexandra Slan offers a panoramic and personal analysis of this issue that affects so many of us.

Her work takes her across the US where she connects with patients, doctors, and researchers whose lives have been defined by the diagnosis crisis like the family with a debilitating condition that went undiagnosed for years until they were able to find answers at the nihs Undiagnosed diseases network.

Or the doctor whose cancer was dismissed by other physicians for years until she was finally able to get a diagnosis. As Serin compassionately demonstrates a diagnosis is more than a note on your medical chart, it can provide a path forward. Treatment options, a supportive community, and the knowledge that you are believed.

The elusive body is a highly relevant and much needed exploration of the diagnosis crisis in this country, and I am so excited to share my conversation with Alexandra with you all. So let's just take a quick break here and get into things.

Alexandra, thank you so much [00:05:00] for joining me today. Welcome to the show.

AS: Thank you so much for having me.

EW: Your book, the Elusive Body, it explores the many factors that prevent someone from receiving an accurate diagnosis sometimes for decades. And before we dive into what some of those individual factors are, I'd love to hear about your journey in writing this book.

Like how did you find yourself drawn to the diagnosis crisis?

AS: I got interested in diagnosis for both professional and personal reasons. I was a health journalist at Time Magazine. And I was discovering that one of the things that readers were emailing me about most often were issues related to their own unresolved diagnostic journey.

So I would hear from people all the time basically asking me, you know, you are interviewing a lot of physicians. Do you have any ideas of someone who could help me? I have been undiagnosed for this long. And it happened frequently enough that it felt like it was something worth looking into. I was just curious, what is it that causes someone to spend such a long period of time undiagnosed.

And then personally, my book is dedicated to my sister Francesca, who has experienced a variety of undiagnosed conditions over the years, and so I have been able to see firsthand how frustrating and destabilizing it can be to be suffering from something for which you have no solid answers. And so I just became very invested in both the scientific questions and also the personal anguish and how to resolve these things.

EW: What results is this really thoughtful and broad ranging perspective on this massive problem that exists not just in the United States, but around the world. And as you describe in your book, millions of people live without a diagnosis, sometimes for decades, and the consequences of that can be extremely challenging, not just from a health standpoint, you know, as their health deteriorates without any treatment or solution, but also emotionally and financially.

And starting with the basics though, what is a diagnosis and how does receiving a correct diagnosis, what does that give someone?

AS: So at its most basic level, a diagnosis is basically an answer to what ails us. It's the identification of a disease or condition that explains the symptoms that a patient is experiencing. But a diagnosis goes so much more beyond that because a diagnosis is also really the beginning, ideally. Of a resolution. So with a diagnosis, a physician can then build a treatment plan that will hopefully provide relief for their patient. A diagnosis is crucial for getting insurance coverage, for said treatment plan or any follow-up appointments, et cetera. A diagnosis is important. If, let's say you have something rare and you want to be in an experimental clinical trial, you need a diagnosis for that. A diagnosis can also create access to a community if there's other people who are suffering from the same condition. And then I also think diagnosis can provide reassurance to people that they are experiencing something that is real and it can provide a kind of coherence to their experience that sometimes has felt very unsettling or chaotic,

EW: and yet some people never receive that clear answer or kind of just linger in that liminal space of this like gray area for such a long time.

And there are many different ways that this can happen in terms of like diagnostic error. Can you tell me about the different types of diagnostic error and how common they are just across the board in the United States, like how many people will receive a diagnostic error each year or within their lifetimes?

It's a startling number.

AS: Yes. Yes, definitely. So in 2015, the National Academies of Sciences, engineering and Medicine set out to do a really comprehensive report to sort of try to wrap their arms around diagnostic error and, and do their best attempt to estimate how great an issue this was and, and try to understand it better.

And basically. That report concluded that most people will experience a diagnostic error in their lifetime, sometimes with devastating consequences, whether that's disability or even death. Some conservative estimates suggest that 5% of American adults experience a diagnostic error every year, so that's something.

10 to 13 million Americans. That is something that many people call a very conservative estimate. So you're [00:10:00] talking about tens of millions of people Among that group of diagnostic error, typically researchers look at diagnostic error in three buckets, more or less, there's a wrong diagnosis. So the answer is incorrect.

You had heart failure, but you were diagnosed with chronic bronchitis. There's delayed diagnosis, so a diagnosis took longer than it should have, so perhaps a delayed diagnosis of cancer. And then there's misdiagnosis, which is someone is never diagnosed, they go on living undiagnosed. And so altogether, those are sort of the three buckets that we tend to, to look at when it comes to diagnostic error.

EW: When it comes to delay diagnosis, what is, is there like a, a bound around what is an acceptable time to diagnosis? You know, when, when does a diagnosis become delayed?

AS: This one is, is a little bit complicated because medicine is inherently uncertain and, and no one expects that something very rare, like a very rare cancer would be diagnosed immediately.

But what they sort of have determined is like, let's say a person comes in and you look back on their medical history and they were complaining about this cyst in their neck for years and years and years and there was never any follow

up. And then you find out it's cancer and it's stage four and, and that is sort of what would be determined as a delayed diagnosis.

It was something that. Generally medicine agrees could have been diagnosed earlier.

EW: Mm-hmm.

AS: But it is, you know, it is complicated. Like sometimes a person comes in complaining of symptoms and there's nothing really coming up on tests yet. But as years go by, perhaps it does develop in into something more serious.

And so there are some understandable questions around, was that initial visit an error or is that just sort of the practice, the standard practice of medicine. So it's, there's some gray area for sure, but I think. It can kind of be some of the, uh, a thing where you, you sort of know it when you see it, like when you find out this was cancer and then you, there's a few people in my book who had this experience.

I think it becomes very frustrating when you've gone to the doctor again and again about with the same complaints and it turns out it was something more serious than, than you were told.

EW: Let's take a quick break and when we get back, there's still so much to discuss.

Welcome back everyone. I've been chatting with Alexandra Serline about her book, the Elusive Body, patients, doctors, and the Diagnosis Crisis. Let's get back into things. I, I wanna get into some of the information or the tools that we use to make a diagnosis. Like how much or how little do we have to know about the mechanisms of a disease or the pathogenesis that this disease takes, and what role does technology play in our ability to more accurately diagnose someone?

AS: So when I was doing the reporting of this book, I was so interested in this question. Every time I would speak to a physician or a clinician who diagnoses and asking them. What exactly are you doing and what is going on in your brain? And it was kind of fun because I think it, it almost becomes innate in some ways.

A physician goes through their medical school, they memorize so many things about the body and how it's supposed to work when it's healthy, and the various

ways that. That things can go wrong and what the body looks like when it's sick and you're memorizing, you know, specific conditions and you're learning about all these different symptoms and what symptoms could be this disease over that one.

But at a very basic level, when a doctor is looking to diagnose, they're looking at a few basic things. First, a person's symptoms. To come in and you say, I am experiencing like a really severe itching pain on my neck. Then they are looking for signs. So does that person have a rash that is corresponding with those symptoms?

And then a medical history. So both a past medical history, for instance, has this person experienced chickenpox in when they were younger and also a recent medical history? What age are they? Are they under severe stress? And then with all of those things together. A physician starts thinking about what is the most likely case here?

You know, someone experiencing like a burning, tingling [00:15:00] and they have a clear rash and they had chickenpox and they were younger, like that could be shingles, and that's something that a physician could figure out very quickly because they would recognize what a shingle rash looks like. They would recognize that this person has had this particular medical history and it all sort of comes together.

Where it gets more complicated is if it's something that can't be resolved that quickly. It's not an immediate, I recognize this. I've seen this a thousand times before in my office, or it's something that shares a lot of symptoms with other things. So many parents might have the experience of going to the pediatrician with a sick kid, and perhaps they want to do a test to know does the child have COVID?

Do they have the flu? Do they have RSV? So then you can do an actual diagnostic test like a swab. And then if there's need for even further interrogation, there's then a variety of different kinds of tests. Like, are you in a situation where you need to be bringing in an ultrasound? You need to peer inside the body you, you know, so there's some things that don't require very many tools at all, and just rely on a physician's medical knowledge and experience, seeing so many patient cases over time, and then some things that will require more investigation and deeper testing and more tools.

EW: At this point in modern medicine, I mean, we have such a wide range of tools in our diagnostic kit more than of course, ever in, in history. We've, we've

got sequencing, blood tests, advanced imaging, and so many more that probably exist that I don't even know about. And many of these technologies have allowed us to make more precise diagnoses.

But as you say, the diagnostic journey pretty much always starts in the exam room with a physical exam. I loved the part in your book when you talk about the history of the physical exam and why it's such a foundational part of this process, and particularly how physical exams are trained or taught in different countries, and I was hoping you could just tell me a little bit more about the physical exam.

AS: Yes. So I'm glad you liked that part of the book. So it was one of the, it was most interesting to me 'cause I got to do a lot of looking back at history, but. You know, the physical exam is so important because it is this beginning, as you said, the beginning of the diagnosis, and it really just starts with observation, which is sort of one of the oldest ways to do medicine.

If you look back at sort of ancient medicine physicians, were really just relying on their own senses. What does the patient look like? What am I hearing when they're coughing and sort of making some assumptions there. And what's kind of amazing is that that is still where it begins. You know, you still enter a doctor's office and you share symptoms and your doctor is observing you sometimes without any tools, often with like a stethoscope or something like that.

But it's kind of amazing that this process of just. Seeing the person in front of you and really listening to them, both listening to their actual, the sounds of their body, but also just listening to what they're telling you are so crucial. And even as you say, you know, today we have so many different tools for diagnosing, but you still need to have that period of just observation and physical exam to even decide.

What tools make sense to bring in at this point at all, and to be able to have that clinical judgment of basically what to do next.

EW: And this, this clinical judgment is something that physicians gain, not just in their training, but through years and years of experience. And I was really struck by the differences in training or testing between the US and the UK for a physical exam.

Could you tell me a little bit more about why there is such a difference or what that difference is in the training for a physical exam and what impact you think it has on our ability to make diagnoses?

AS: You know, physicians everywhere learn a physical exam. But what's interesting is the way that young doctors learn that exam and are sort of tested on their ability to glean a diagnosis from it.

So the United States has a very long tradition of young doctors following a more senior physician through, you know, rounds at the patient's bedside and sort of watching. That physician do an exam and then they might discuss it afterwards, and they do have that sort of back and forth discussion. However, what's different, something that is done in the UK in medical school is that young doctors are actually, they themselves are observed doing the physical exam by a more senior doctor, and then they are tested on [00:20:00] it.

And that test. Is very crucially important to whether they get to become a physician in the first place. So what ends up happening is a young doctor then goes through these periods where they're observed by someone and they're actually watching. Did you do every step of the physical exam that you should have?

Is there anything that you missed a, you know, a question you didn't ask, or the way that you held that patient's foot, like you missed something? Are you listening to the heart in the right way? And they really have to train for that because they will undergo an exam in which those skills are basically rated.

And it's, it's sort of almost like a pass fail. And if you aren't able to get the correct diagnosis purely out of this physical exam, you don't continue on. Um, or you sort of, you, you have to go back and, and, and retake it. So what some physicians at Johns Hopkins, as well as Northwestern University now have done is they're trying to find a way to incorporate that kind of testing into.

A US medical school system to basically ensure that young physicians today can still do the physical exam and can still reach a diagnosis. Without necessarily needing all the tools they, they do have at their disposal. And of course they should still use them. Like ultrasounds are amazing and doctors should know how to, how to use them.

But there is this effort to try to make sure that the. Sort of skills that come from a physical exam are not lost over time. And you know what they do find is you

can get very far in a diagnosis from the physical exam still today without necessarily needing to use the technology. The more ideal balance would be.

Doing a physical exam, really reaching a pretty firm hypothesis of what's happening and then deciding, you know, now I do think I actually need an ultrasound, or Now I do think I need these extra. Um, imaging tests or what have you. But yeah, it's, it's very interesting and it's amazing to watch if anyone has opportunity to, to, you know, look up on YouTube, like UK Doctor doing physical exam.

Um, it, there's some pretty incredible, uh, examples.

EW: Just to zoom in on the last 150 years, which is this time when our capacity for diagnosis really grew as a result of better understanding the mechanistic basis of disease, and as we develop tools that allow us to glimpse inside the body, how did the diagnostic process evolve to what it was today or to what it is today?

Like what are some of the broad patterns that you see?

AS: Definitely. So you have like 150 years ago, germ theory is starting to, uh, really gain traction. So there is this understanding of different things that actually cause disease. You're starting to get different kinds of imaging over time so you can peer inside the body, not just observe the outside of the body.

And then you're also getting the ability to. Decode the body with genetic sequencing. And so diagnosis is becoming more scientific, more precise. There's, you know, ways to basically, as a single physician get a second opinion just through different technologies. That's amazing. Like you are more likely to be diagnosed with your rare disease today than you were 150 years ago.

What I think is, is then challenging is for people who don't get a diagnosis. Now, the experience, I think can feel especially fraught because you feel like. Science has come so far. There are so many different tools to use to diagnose, and so if I can't get a diagnosis, then you really just feel so isolated, lonely, confused, scared, and so I think what's been interesting is that diagnostic error has existed forever.

EW: Mm-hmm.

AS: And people living undiagnosed has existed. Forever, but in this moment where it's like this really is an era of huge scientific progress when it comes to diagnosis. I think falling through the cracks can feel extra heightened now

EW: as our diagnostic tools and our scientific knowledge has advanced so rapidly, especially over the last few decades, diagnoses themselves have changed.

They've become kind of these moving targets sometimes where a diagnosis that existed 10 years ago might not exist today or might be broken up into different levels. How does that. Moving target [00:25:00] aspect of diagnoses, how does that contribute to the diagnosis crisis?

AS: Yes it is. It is interesting. As you mentioned, the diagnosis isn't necessarily fixed.

Definitions of disease change, new conditions are discovered. Scientific knowledge progresses and you know, we understand new things about about the human body. There's new biomarkers that can be taken into consideration. I think it can complicate the crisis a bit in that. Perhaps decades, a hundred years ago, whatever you had, you would've had a diagnosis for it.

It would've been like. Melancholia or you know, it just would've been something that was sort of this, yeah, this like grab bag of things and now because we science requires more precision, sometimes when things don't fit exactly into these categories, I think it can create a lot of uncertainty.

Specifically, I think. There's sort of this category of patients who have what's sometimes called medically unexplained illnesses, so they have a lot of symptoms like fatigue, brain fog, headaches. Uh, but perhaps not a lot of signs. Like there's, there's no rash, there's no fever, there's nothing that's coming up on a diagnostic test.

And, you know, perhaps in the past, again, maybe it wouldn't have been a great diagnosis, but like you might have been put into some kind of category. Um, again, that's probably, you know, not for the best, but, but today. That remains very difficult and complicated. And sometimes you don't know, am I experiencing something totally unknown that nobody's ever gonna figure out?

Or am I sort of at the edge of modern medical knowledge and maybe in 10 years there will be sort of an understanding of, of what I have. So there's some uncertainty there for sure. That's hard to grapple with.

EW: Let's take a quick break here. We'll be back before you know it.

Welcome back everyone. I'm here chatting with the wonderful Alexandra Serline about her book The Elusive Body. Let's get into some more questions. This unevenness of uncertainty contributes to diagnostic error not being distributed evenly in different populations or with different diseases or different types of diseases.

What are some of the patterns that we see, whether it's patient population or types of disease that are most likely to be associated with diagnostic error? And what are some of the reasons for these patterns?

AS: People who have rare or like a novel disease experience very long diagnostic journeys. Often and often when I speak to people with, with rare diseases, they'll talk either about years and years going without answers.

Or going without correct answers. Like they, they actually did have several diagnoses at different times, but none of them were quite right. And maybe that was even explained to them. Like, this feels like most similar to this diagnosis, but we're not totally certain. And so people with rare illnesses have long diagnostic journeys, typically, just simply because they are rare.

Physicians don't see them as often as they do other things. So it can take a lot of time and then. The second group I would say are the, the sort of patient category I was referencing before are people with so-called medically unexplained illnesses. Basically people experiencing a lot of symptoms, but not a lot of signs of illness.

So again, symptoms like fatigue, headaches. Not quite feeling like myself, I can't sleep. You know, there's a variety of things like that that don't necessarily show up on a thermometer or a test for various viruses or the standard test that a physician might do, or even just the physician is trying to do the physical exam and there's no, there's no rash, there's no, they're struggling to piece it together, and I think.

For that category of people living, misdiagnosed or without a diagnosis for a long period of time can be more common.

EW: If you look at all of the different people who are living with a diagnostic error, there's a subset that is able to be diagnosed but is not for some reason. How much of that reason or how much is of that pool is because it's not been

high priority to investigate some of these unexplained diseases, or is the research funding just not there?

And so where [00:30:00] is their clearest room for improvement in your opinion?

AS: I, I really do feel like this requires improvement at almost all levels, but it is definitely, it would benefit from a systems level solution, so on just like a very basic level. Diagnostic error is despite the fact that I think getting a correct diagnosis is perhaps something that matters immensely to most people who go to see their physician.

It's not a very widely recognized problem. Among medicine and, and, and the public. It gets not the same level of attention as, as other things do. And so I think first and foremost it would be sort of a recognition that diagnosis. Has evolved in these many different ways, and yet it still is something that could be improved upon, you know, even in the United States.

But I think some common issues that I've run into from both talking to patients and talking to physicians about diagnostic error is that everyone feels a bit frustrated with the healthcare experience right now in appointments. If you can get one with the primary care doctor. Are often very short, which sometimes is okay if it's something like shingles and a doctor has seen it many, many times and they see it, they diagnose it, they give you a prescription, like in some cases short is okay, but in a more complicated situation it's really not.

And a lot of patients feel like it's so hard to get an appointment with a physician, it can take months. And then when you're there, it's a very short appointment. And for the physician, that's also not necessarily a great experience. They're having to see more patients in shorter periods of time. Burnout is really high.

You can be distracted or feel rushed, and problems can emerge, and so I think everyone is desiring a little bit more humanity injected into the system, whether it is simply the opportunity to have. Longer appointments or to have just more continuity in care. Often people who have experienced long periods undiagnosed, you talk to them and they've seen like eight different doctors, and they are often feeling like they're bringing their own medical information from physician to physician to physician, and people aren't talking to each other.

And so I think in some ways the way that the system is organized right now is not very conducive. To the time that a complicated diagnosis might, might need,

and also diagnosis often works best when it's a team effort. And so finding ways to involve. You know, not just the physician, but the nurse who's in the room.

You know, finding more ways to, to, for the patient to feel kind of empowered to share more. It really is something that I think from, you know, the top down, we would greatly benefit from sort of rethinking the way we're doing things now.

EW: I agree, and in some areas, just geographically speaking, it might be more difficult to implement than in others.

This sort of collaboration, bringing everyone on board and you share the story in, in your book of the Proctor family, which had several members that had very long and frustrating diagnostic journeys before they finally found an answer. Could you tell me about a little bit about their story and how they ultimately connected with the Undiagnosed Diseases program, which is just an incredible program?

AS: Yes. Yes. We'll happily talk about them. So the Proctor Family is a family of five siblings from very rural Kentucky, and the oldest is Louise. And when she was around 25 years old, she first started experiencing. These episodes where basically she would be walking for anywhere from five to 10 minutes and all of a sudden she would basically freeze in place.

She, it felt like her legs and her feet were almost becoming like rocks, and it was so painful that it felt like she couldn't move any further. And over time she was the eldest of these five siblings. Over time, every single sibling started experiencing this same condition, but being in rural Kentucky, you know, they would all go see their physician and there was only so much that could be done.

They would be given diagnoses of perhaps it was, it was early arthritis, but that actually didn't seem right and they weren't responding to standard of care. [00:35:00] They would go see specialists throughout the state and nobody seemed to have any answers. And finally. It had been something like 30 years and Louise went to her doctor and was just desperate like that.

I am so desperate. We need to find something or someone to help us because this is just untenable. And thankfully, her doctor had found out about the Undiagnosed Diseases program, which is run by the National Institutes of Health. And at this time it had just recently started and basically. This program at the NIH is this group of clinicians and researchers from a variety of different disciplines.

Who come together to crack the most complicated medical mysteries. It's led by this geneticist and pediatrician, Dr. William Gaul, and they basically accept applications from across the country of people who have something that has boggled the minds of, of all the physicians that they have seen and, and that doctors have recognized.

Like, I don't think I have anything else. I, I don't know what this is. So they send them to this NIH program, which has now become the Undiagnosed Diseases Network. And there are some similar programs across the country at University Medical Centers. But what's so amazing about this program is. What they do is they bring together a group of experts in different categories.

So you have a geneticist, a cardiologist, a neurologist, there could be a dermatologist, and they meet and discuss the patient before they even show up. So already this group of experts has combed over their medical history, seen all the imaging that they've done. And then they develop a sort of plan for how they're going to try to do this diagnosis.

The patient or in this, or in the Proctor family case. The entire family, it was all five siblings and their parents went to the NIH. And they spent an entire week going through various testing, you know, just really long appointments, doing a lot of genetic testing, and ultimately it was discovered that all five siblings have a very rare genetic disease called arterial calcification due to deficiency of CD 73.

They call it a CDC for short, but it was. It was a never seen before genetic, incredibly rare genetic disorder, and they were the first cracked case of the undiagnosed diseases program, which has gone on to diagnose many, many, many more Americans. But it was really amazing because, you know, this group living in rural Kentucky didn't necessarily have access to, you know, the best of the best diagnostic technologies.

And so through the NIH, they were able to get diagnosed after years.

EW: I think it's remarkable what this program has been shown to do and the potential that this program has, which also is. Alarming. Considering the recent cuts to basic research, E especially given that research into rare diseases is so, tends to be such a challenging thing in the first place.

Can you speak anymore to what the, what the horizon looks like for rare disease programs like this and just research in general given the recent cuts from this administration?

AS: Definitely so. Rare diseases, of course, by definition affect small populations. So in general. Rare diseases tend to really struggle to get research funding.

Definitely struggle to get funding on par with more common ailments, so getting funding from the NIH or having federal support is hugely important because it is very difficult for private industry or a private pharmaceutical company to take on the cost of a clinical trial for something that is going to affect a small number.

It's just difficult. It's difficult math to make work. So having federal funding and having support in that way is hugely important. And what was very scary for the rare disease community was when there was a proposed 40% cut to the NIH budget. Thankfully that did end up being rejected largely thanks to advocates and lawmakers.

That full cut didn't end up happening. But where there remains concerns is that. Because it is so difficult to get funding. Ideally, the rare disease research infrastructure has some semblance of stability, so having a kind of uncertain future that perhaps this funding that had been somewhat consistent could just go away very quickly.[00:40:00]

Is very difficult because you need the certainty so that scientists want to do this research and feel like there's a path forward to continue this kind of research. And so the uncertainty created by those cuts has shaken a research community that requires a lot of resources and people who are willing to dedicate their careers to it, um, over a very long period of time.

And that kind of system really requires stability.

EW: Your discussion of the Proctor family and your sharing their experience highlighted a few things for me that are so fundamental too, not just to the impact of a, a diagnostic error on an individual or on an individual family, but just the general impact on.

Trust in science and medicine overall. As we talked about in the beginning, science has advanced so rapidly and so when it can't provide a diagnosis, when your doctor says, well, I don't know, so it's not me, it's you. This kind of. Fuels mistrust in science and medicine, and it might push people to seek alternative therapies that where someone says, is not afraid to make the claim of this will cure you even though it won't.

So can you, can you talk a little bit more about how you think the diagnosis crisis has contributed to this rise of mistrust?

AS: When someone doesn't get a diagnosis or if they are just spending a very long period of time physically suffering and feeling like nobody is providing any answers. Or they feel like they sort of have had to take on the burden themselves to figure this out.

They feel very alone, very isolated and scared. I, I feel like those are three of the emotions that many of the people I spoke to for this book would, would talk about just feeling like. Abandoned basically. And many do have empathy for what physicians are going through as well. It can be a very frustrating experience as a doctor.

You go into medicine because you want to help people and if you cannot help the person in front of you, you too are, are frustrated and sort of feeling. Pretty bad. But what I think happens for some patients is they don't just decide like, okay, well I guess I'll just go about my day, and that's that. You know, they can end up going to alternative sources outside of the mainstream medical system, and in some cases that might be okay, but in some cases it might not.

There's a lot of people trying to sell you things online, especially when it comes to health and medicine that. You know, in the best case scenario, don't work. And in the worst case scenario could be really harmful. I think there's just been somewhat of a breakdown in trust that would benefit again from feeling like when you interact with the medical system, you are engaging with a humane system meant to help you.

And I think on both sides, patients and physicians often feel like they are engaging in a system that's not like that. That again, appointments are rushed. People who have more complicated diagnoses feel like they're being dumped from physician to physician. And everybody's really frustrated, and I think there would be a lot of faith restored if it felt for both patients and doctors that were kind of more in this together, that even if this is going to be a situation on which there's not going to be a quick answer, we're sort of still together on this path, figuring out how to navigate the uncertainty that is inherent to medicine that's not just gonna disappear even, you know, with all this scientific progress.

But I think that sort of faith in medicine really needs to be restored.

EW: It does, and I, I'm so glad you mentioned this, this facet of uncertainty, being a part of medicine, like by design uncertainty is built into science. It's

built into medicine. Can you tell me more about uncertainty in medicine and why it's so important to acknowledge?

AS: Yes. I mean, this is one, one thing that's maybe surprised me more than it should have, but when I was talking to many. Physicians about diagnosis and, and you know, what is it like for you if you're in a situation in which you really don't know what is going on, um, which you know is going to happen, but so many would talk about how deeply uncomfortable it can be and that.

Sometimes medicine can have this culture of the doctor is supposed to be this basically genius person [00:45:00] who you know is, is supposed to have all the answers at all times. Ideally, they're like Dr. House and they just know everything based on like a quick appointment. And it's just, it can be sort of too hard to live up to, but also uncertainty and navigating that is often not something that is very explicitly discussed in medical school, for instance.

I do think that's changing, which is great, but I think for a very long time, nobody's really given the tools or even a script for what to say in a moment with a patient when you. Don't have an answer for them, and you do want to make clear that I'm struggling to find an answer. I don't wanna totally discourage you.

And sometimes they just literally don't know what to say because nobody has really talked them through it. Because even though medicine has this inherent uncertainty to it, it's not necessarily always been a culture that's been comfortable acknowledging that. And so I think some of the. The diagnosticians that I've spoken to in my book who are really skilled, are also really skilled at having the discussion with a patient when they don't know the answer and creating a kind of plan and kind of being willing to check back in and, and sort of.

Be very open about the uncertainty, but in a way that isn't discouraging, but is just sort of acknowledging the reality of the, of the situation. But typically, it's required that person to have made a conscious effort to talk about that and sort of talk about it with their colleagues and sort of be more open to embracing the fact that they're not gonna have all of the answers.

Sometimes diagnostic error is not talked about because a health system worries that even focusing on the fact that they don't get the diagnosis correct all the time would open them up to some sort of like legal repercussions, which I, I do understand, but what, what ends up happening is no one talking about it.

So a lot of the doctors who I interviewed in my book. In their own personal practice, what they will sometimes do is track, let's say like two weeks worth of cases of people that they saw and look at how they ended the, the visit, if I diagnosed them with x. Or why, and then they go and try to follow up and figure out was that actually the correct diagnosis?

Because so often a physician who's maybe seeing a patient in an emergency room situation or something like that, they may never even know that they didn't get the diagnosis right. Nobody is following up to, to let them know that, that it was incorrect. And so it can sometimes take some conscious effort and being open to the idea that I know for a fact that there's no way that I have gotten the diagnosis right every single time, and I want to actually go back and see where did I get it wrong and try to understand what happened.

Was it just that was a particularly complicated case and one would've gotten it wrong, or was it at the end of my shift and I was really tired? And did I miss something I shouldn't have? And how can I, how does that experience inform what I do next time? But I do think that requires a little bit of humility on the physician's part to even want to go back and look at where they may be aired, where.

EW: So many of us have experienced firsthand or secondhand with diagnostic error waiting forever. Having your doctor feel like they're not listening to you and feeling like, yes, this is my story. That person has a story, that person has a story. But what I loved about your book is that you are pulling out the common threads throughout these stories and saying, what is the bigger picture here?

What are the, the, the, the issues that are guiding this and how, what can we do about it? And I, I just really appreciated it and I appreciate also so much you taking the time to chat with me today. So thank you so much for coming on the show.

AS: Thank you so much for having me.

EW: A big thank you again to Alexandra Ferlin for taking the time to chat with me. If you enjoyed today's episode and would like to learn more, check out our website. This podcast will kill you.com, where I'll post a link to where you can find the elusive body patient's, doctors, and the diagnosis crisis, as well as a link to Alexandra's website where you can find her other incredible work.[00:50:00]

And don't forget, you can check out our website for all sorts of other cool things, including but not limited to transcripts, quarantining recipes, show notes

and references for all of our episodes. Links to merch. Our bookshop.org affiliate page, our good reads list, a firsthand account form, and music by blood mobile.

Speaking of which, thank you to Blood Mobile for providing the music for this episode and all of our episodes. Thank you to Liana Sachi and Tom Bri Fogel for our audio mixing. And thanks to you listeners for listening. I hope you liked this episode and are loving being part of the T-P-W-K-Y Book Club. A special thank you as always to our fantastic patrons.

We appreciate your support so very much. Well, until next time, keep washing those hands.