all right well I think we should go ahead and get started um I want to welcome everybody to Medicine Grand rounds today on this

2:47

first day of November today I'm very excited to have a topic that many people have expressed interest

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in hearing more about which is medical misinformation clearly one of the you 3:00

know real challenges I think of the last several years and something that has moved to the Forefront of many of our

3:06

thoughts so we have a fantastic guest who is going to speak to us about this Dr David 3:13

scales is a physician and medical sociologist at Weill Cornell medicine and he's the chief medical officer at

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kritika critica critica and NGO focused on building scientific literacy

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um his PhD dissertation examined the global governance of infectious disease and he completed a postdoc at healthmap.org at Harvard Medical School

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and spatial epidemiology he then completed a primary care Internal Medicine Residency at Cambridge Health

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Alliance and he practices as a hospitalist his current research however focuses on medical communication in clinical and

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online settings including understanding how to address misinformation within digital communities his work seeks to

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emphasize how structural factors affect our information environments to allow misinformation to propagate and

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misconceptions to persist he leverages qualitative and quantitative methods to address 4:01

misinformation training infidemiologists to build covid-19 vaccine confidence in 4:06

online communities with community-oriented motivational interviewing he's written about applying models of epidemic disease surveillance 4:12

and responses that Guide to the problem of misinformation and he served as a consultant to the office of the Surgeon General on the topic of the impact of 4:19

covid-19 misinformation during that pandemic in his spare time he enjoys learning and speaking different

languages biking playing water polo and reading with his two-year-old son all 4:30

awesome things so Dr scales David thank you so much for joining us today and I'm 4:36

really looking forward to hearing you shed some light on this conundrum 4:42

thank you Wendy it's an honor to be here I'm looking forward to talking to you all this is obviously a very large topic

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so I just hope to kind of provide a little bit of the framework and some examples that might um assist in some of

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your thinking as you guys are working with patients and inevitably encountering patients that

5:00

um that have uh perspectives that might be informed by misinformation so my talk 5:05

today is called the toxins we carry and I'm going to go into why I specifically talk about why are we talking about

5:11

toxins tackling medical misinformation Beyond covid-19 vaccine hesitancy 5:17

so just to disclose so I'm a consultant for the office of the Surgeon General 5:22

and CMO for critica as Wendy mentioned um critica is an NGO we're primarily 5:28

funded through the Robert Johnson Foundation uh just also want to acknowledge the people that I work with so Jack and

5:35

Sarah Gorman who started critica um Dr BK titanji who some of you might know uh from the Department of

5:40

infectious diseases at Emory um Tyler Starks is a major collaborator at Hunter our info demiologists

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um our collaborator at the Annenberg School of communication at the University of Pennsylvania Kathleen Hall Jamison and of course our Founders the 5:54

Robert Johnson Foundation so what are we going to talk about today 6:00

so first we're going to try to get on the same page about what are we talking about when we talk about misinformation

6:06

then I'm going to try to describe to you how we have moved how our information ecosystem has moved from the need for

traditional types of of message-based communication to more networked health 6:19

communication and how message-based to environmental models of information Health can shape the way that we think

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about how we can address this problem and then specifically how we can operationalize I this information

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environment framework to broadly address medical misinformation even at the point of care which I know might sound

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overwhelming but I'm hoping by the end of this talk you might be in agreement with me that we as clinicians have a

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role to play even if a lot of the problems in our kind of misinformation uh kind of infodemic as it were are

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structural so to start with so this is a a figure

7:01

that looks at information disorder on a spectrum from false to kind of things 7:07

that have an intent to harm and the Spectrum runs from misinformation all the way to disinformation and Mal

7:12

information and what determines where you are on that spectrum is often related to the motives behind why

7:19

someone is repeating or sharing information so because we often don't know someone's

7:25

motives I tend to prefer the term misinformation which is information that 7:31

has a false connection or is misleading um because if we don't know someone's 7:37

intentions I can't claim that it's disinformation or mal information um if you look at the bottom of the

7:43

screen you'll see BS lies and manipulation essentially as a shorthand way to think about this

7:49

um if this is something that's interesting to you I recommend the book on BS um which the actually written out not

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just the initials by Harry Frankfort um where he defines BS essentially his true or false statements unconnected to

a concern for the truth which I think when we think about how information spreads online I think that term

8:09

actually captures a lot of it so you will hear me use the term misinformation 8:14

um but please keep in mind that it could also include disinformation of Mal information depending on the intent of

8:20

those that are spreading the information um and we've all seen this I like to 8:26

point out this article I brainwashed myself with the Internet by Brandy zadrosney because you know number one

8:32

this isn't necessarily all about covet and it's not necessarily about Internal Medicine there's misinformation that of

8:38

medical consequence in many different topics in every corner of the internet this is an unfortunate very unfortunate

8:46

um report that zidrozny published and published just before the pandemic and I 8:51

like to use this as an example to show that like while a lot of us kind of came to consciousness of this problem and the

8:58

scale of this problem with the pandemic this is a problem that predated the pandemic and in my specific trajectory

9:05

here was uh when I worked as a reporter and I started to see reports about uh 9:12

things that seemed like misinformation you might you guys might have heard about goop um and making unsubstantiated

9:18

claims about the health impact of its vaginal eggs uh you might have read things about Lyme

9:25

disease and so in some of the reporting that I did for WBUR I spent a lot of time 9:31

um in both online and physical communities with people who believe that they are suffering from a manifestation

9:38

of of what they would term as chronic lyme disease um uh talking to providers that provides

9:44

services along this Paradigm and patients who are suffering from symptoms 9:51

um that they attribute to chronic lyme disease and the thing that I say about this is it's clear that they're suffering but it's less clear to me what

9:57

they're suffering from and this is a transnational phenomenon some of the research that I did

10:02

um in reporting took me to France where I looked at a similar manifestation of the transnationality of misinformation

10:09

about Lyme disease and some of the challenges in trying to address this so my own Pathway to misinformation came

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essentially from that experience as well as the experiences that I've had 10:23

um as a hospital medicine attending I had one patient a 29 year old woman with crohn's disease who had anal fistulas

10:31

uncontrolled Crohn's uh bright red blood per rectum but multiple admits over 10:36

serious months for inability to tolerate po while she was refusing biologic 10:41

therapy and persistently asking for tpn even though she really didn't meet 10:46

indications for it because she wasn't really on the fullest extent of her treatment 10:52

there was another patient that I had was 58 year old woman who actually had a diagnosis of ehlers-danlos she had

10:58

actually gone to the farthest reached and gone to Johns Hopkins so she could meet with geneticists who'd actually

11:05

test her for ehlers-danlos and presented with multiple admissions secondary to shortness of breath acute on chronic

11:11

lymphedema and she had diastolic congestive heart failure the challenge with both of these

11:17

patients was the how they insisted almost every single one of their sisters 11:23

symptoms was related to the specific disease that they were presenting with 11:28

um and um and some of the resistance that I faced as a provider in trying to 11:34

persuade them to accept a standard of care treatments this is this is not 11:40

uncommon I mean I think we can see manifestations of medical misinformation even outside of covid outside of the

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pandemic we see this with the gospel of Wellness this is a book by Rina Rafael that was um just published in September

11:53

we also see this in the phenomenon that social scientists describe as contested 11:59

illnesses now these are illnesses around which there is a um a a lot of 12:05

uncertainty to give an example of a content of contested illnesses these are things like chronic lyme diseases I

12:11

mentioned um irritable bowel syndrome um uh inflammatory bowel disease ehlers 12:17

donmos myalgia encephalomyelitis formerly called chronic fatigue syndrome Gulf War syndrome Mast Cell Activation

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Syndrome and even long covet I think as clinicians we can all think about you know we might have in our mind kind of

12:31

patients that we might have seen with one or more of these these illnesses and 12:36

found ourselves in some sort of impasse some sort of disagreement where our 12:41

perspective on the illness was different than theirs and the thing that I like to say about this is like like all

12:48

misinformation there are kernels of Truth and with almost all of these

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diseases there is there is a degree of scientific consensus you know with chronic lyme disease there is a

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discussion about we all know about Lyme disease itself there's a increasing recognition of what's called

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post-treatment Lyme disease syndrome which has very specific criteria long covid we're starting to see specific

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criteria as well there I'm the issue with contested illness is is that in at 13:17

times sometimes the illness itself is contested whether or not Physicians actually believe it exists is in

13:24

question but there's usually a kernel of Truth where we can agree that there is some sort of disease that exists then there's

a large penumbra around that consensus where there's a lot of uncertainty and 13:36

in this uncertainty there's uh advocacy networks of online patient groups that 13:43

are sharing information and sharing essentially defining what constitutes the facts for the

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disease and I met I talk about this because my patient with ehlers-danlos syndrome had clearly spent a lot of time

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in these networks and and was convinced that pretty much all of her symptoms were related specifically to Euler's

14:02

Dominos syndrome and the challenge that I had as a physician is I didn't know there's a lot of

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uncertainty a lot of what she was suggesting was in this penumbra of uncertainty but I'm going to talk a

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little bit later about how I approach patients like this to try to get to a

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little bit more of a detaunt where we can start to move forward um even if we disagree about

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um or feel different degrees of certainty with regard to uh aspects of

14:31

their illness there's a lot of ways where we can find agreement and move forward on a treatment plan

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first let's talk a little bit how we got here and some of the Frameworks for how we might address this problem writ large

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and then dive into the clinical aspects so how did we get here so first is the 14:50

idea that uh as many of you have probably been taught if you've spent time in the laboratory that good science

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speaks for itself good scientists basically publish their papers and then then just let the scientific discussion

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happen but in our current information ecosystem science doesn't speak for itself science happens at the speed of a

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tweet um there's a number of preprints that have gone viral on Twitter there's a 15:14

number of uh you know aspects where one specific study gets taken out of context 15:19 or cherry-picked and Amplified in certain settings and becomes from the perspective of of people that are in 15:28 certain disease communities um uh a scientific fact so this process of how scientific facts become 15:35 essentially socially mediated to become facts it has changed in the setting of 15:41 our current information ecosystem and I would say science hasn't really caught up with that 15:47 this is also amidst an overall media environment where there's declining influence of traditional media 15:53 structures this is due to a long history of deregulation Financial crippling of 15:58 newspapers due to the internet due to social media and also declining the influence of both television and radio 16:06 this is in the context of a rise of these New Media structures and various 16:11 different incentives for engagement this leads to a situation where there's misinformation or even positive 16:18 misinformation has the potential to spread at unprecedented speed and scale 16:24 and for those who are interested I highly recommend this book Network propaganda by uh Yokai benkler and his 16:30 colleagues it's about politics um but what I would say is specifically chapter 11 isn't about politics at all 16:37 it's about exactly what we're talking about here with regard to the structures that have facilitated in an environment 16:43 that allows misinformation to spread virally 16:48 so what does this look like for health communication so health communication 16:53 for a long time has been message based where there's a lot of thought and time 16:59 and energy that goes into crafting the message that's because scientists are trying to kind of understand what the 17:04

facts are they're communicating to you know scientific advisory panels who are synthesizing some of the data publishing

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in scientific journals and pre-prints um that information gets aggregated by 17:17

public health practitioners who are trying to decide kind of what public policy should look like based on the science and we are also doing this as

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healthcare workers and clinicians but then some of these messages they need to get transmitted to the public so Public

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Health practitioners were often in the past leveraging media and journalists this through they would do this through

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relationships they might have had with reporters through press conferences and ultimately it would reach the public but

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this isn't really how health communication is happening anymore and we saw this during the pandemic

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there's a certain manifestation of networked health communication where in 17:54

a lot of environments online in particular all of these stakeholders are communicating with each other now to be

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clear I'm not trying to argue that message-based communication doesn't exist at all or isn't important but the

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relative proportion the relative importance of message-based communication in the Walter Cronkite era

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versus now I think we can all agree that there's been a pretty significant shift in terms of the importance relative to

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where people are getting a lot of their information of Health consequence so what is this networked health

18:29

communication mean so this means that I I I like the quotation that that uh 18:35

young and Miller uh wrote about here but they say today's media users experience decentralized

18:41

interpersonal horizontal networked politically relevant communication every 18:47

day now it's decentralized because no one really controls the narrative it's 18:53

interpersonal because a lot of this is based on the individual contacts that we have with other people whether that's

18:59

someone that we know personally like our friends and family or the fact that I can follow LeBron James on Twitter

19:06

um the influence is not determined by expertise it's determined essentially by 19:11

engagement attention the number of followers that you might have this tends to prioritize uh Communications that

19:18

leverage emotions over rationality so this also manifests as a horizontal 19:24

Network where it's non-hierarchical expertise doesn't nearly matter doesn't 19:29

matter nearly as much as some of the other factors that we've talked about um this makes information not in this

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message-based top-down type of structure but messages travel from one person to the other

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its networks because net nested groups of individuals and communities are sharing information especially those

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that have shared identities or shared values or some sense of however they Define community rather than some sort

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of uh experts bestowing their knowledge upon the public and it's politically relevant I think

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this is really important because um you know as we talk about health-based information that's often

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what what social scientists would call an ethic perspective that's the perspective of of Outsiders of people

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like us as Healthcare Providers but from within the communities themselves kind 20:21

of what what social scientists would call the emic perspective a lot of times these aren't health

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issues at all these are political issues if we're talking about abortion if we're talking about vaccination

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to a lot of people that's not a health issue it's a religious one it's a value-based one or it's or it's a

political one about their expressions of free speech and that's an important thing for us to recognize is even the framing of what 20:45 types of issues these are these health issues or are these something else is something that experts don't 20:51 necessarily have a monopoly on in terms of that framing 20:56 so what does this mean practically speaking so I'd like to show this 21:01 network map because this is this is a specific example so let's go back this 21:07 is uh this is California Circa 2015 2016 and this is a network map of Twitter 21:13 conversations um from uh people talking about vaccines and a specific State Bill State Bill 277 21:22 that was designed to prove to essentially end personal belief exemptions from vaccination 21:28 so what you see here you see clusters of different essentially interest groups talking to each other on Twitter 21:35 so the orange group at the bottom that's autism um these are people who are specifically 21:41 talking about autism and its relationship to vaccines and each bubble there represents essentially a Twitter 21:46 user that that bubble is a node and the size of that node is the number of followers that they have and the 21:52 connections between each node are essentially how often they are speaking to or linking to one another including a 21:59 uh you know both specific connections with a at someone in their tweets or if 22:04 they're following so if orange is autism we can also see pink is specifically a 22:12 community focused around anti-vaccine the blue is the medical Freedom 22:17 Community this is also about the time that there was a the tea party uh 22:23 contingent of political activists was very active and that's the teal over on the right and that somewhat tiny

Community Way On The Fringe that doesn't really seem to have much connections to anyone else is actually the the public

22:37

health Pro vaccine community but I like to show this figure um because this is this is the problem

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that public health has um in communication about information of

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Health consequence is already networked and yet public health communication our medical communication of consequence is

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not networked we are still very much in a message-based paradigm um that falls victim to the Field of

23:03

Dreams fallacy the idea that if you build it they will come but we need to uh switch our approach to a more

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networked type of of communication so we've seen this this isn't just about 23:17

vaccines there's some other papers that look at the network structures looking at discussions around Ebola the vaccines

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but in a slightly different framework in zika and I apologize for the for the quality of these images the images are

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of poor quality in the papers themselves but uh just describing them briefly these are essentially

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um maps of the different stakeholders that are having discussions about these issues with yellow tending to be more

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mainstream type media um blue tending to be a little bit more kind of uh user created green tends to

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be essentially very medically oriented and the Oren sorry not the orange the um 23:59

the magenta is uh the Public Health Community and similar to the previous slide you can see that the public health

24:05

discussions are not really integrated into the network off to the periphery and relatively small

24:12

um compared to the larger discussion at hand this is you know this is 24:17

challenging these Network maps are trying to capture what I think a lot of people feel when they're in an online 24:23 space but I will say I think that the empirical science behind these these Network Maps still leaves a lot to be 24:30 desired for us to kind of feel conclusively uh feel uh rigorous in our conclusions that we can draw from them 24:35 but the thing that I do like to say is I think it's pretty clear that public health tends to be on the periphery of 24:41 these networked discussions so I've spoken previously about how we 24:46 can start to see uh this problem writ large of information of Health 24:52 consequence um being spread and affecting people's behaviors and perspectives 24:58 um this has been described by the World Health Organization as an infodemic as an overabundance of information and I've 25:04 spoken about this previously um I in an article talking about um how we can perceive this as uh 25:12 essentially the same mechanisms and the same manifestations as we perceive of infectious diseases 25:18 communicable diseases ultimately communicate and if we can understand kind of the connections in these 25:25 metaphors and what type of uh of window this gives us into our type our response 25:32 to this I think that's an important thing that we can take away because we can do surveillance on misinformation we 25:37 can do diagnosis we can do responses we can also be working on prevention 25:43 so but I would argue that this model is insufficient because you know when we think about our Public Health we can 25:51 think about the fact that you know uh 150 years ago there were constant 25:56 epidemics all the time it took a certain amount of Sanitation it took a certain amount of of getting toxins and 26:03

pathogens under control before we could really start to focus on an outbreak oriented approach we first had to start

26:10

with the sanitary and a hygiene-based approach so this so environmental 26:16

thinking is is one that I'm not the first one to kind of talk about this metaphor Whitney Phillips who's a

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Communications professor at Syracuse University has written a number of pieces about this including this piece in Columbia journalism review talking

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about the toxins we carry and I think it's an important perspective because it helps us shift from a message based to

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an environment-based model of information health and it also helps us recognize that the

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goal here is not to completely eradicate kind of our information ecosystem of 26:47

misinformation that's impossible just just like it's impossible to eradicate 26:52

our entire um world of toxins um the goal is really to render

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misinformation as harmless as possible and there's a lot we can take from an environmental health framework to do

27:04

that now environmental health Frameworks are complicated so similar to an infectious 27:11

disease framework we're not necessarily trying to adapt everything we're not trying to to figure out the r naught of

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every bit of misinformation similarly there's aspects of uh you know 27:23

environmental health and toxicology that can apply to what we're talking about here but we're not necessarily going to

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try to dive in at this level let's just step back uh kind of a main

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tenet of Toxicology which is the idea that dose makes the poison uh anyone 27:39

who's worked as a hospitalist on an internal medicine board has uh has seen patients who have come in with with

27:46

essentially water toxicity with hyponatremia we the the dose is what 27:51

makes the poison caffeine can be poisonous at certain Doses and sodium fluoroacetate also known as 1080 which 27:58 is can be a very harmful inhibitor of the of the Krebs cycle and metabolic components of our body 28:05 um it requires much less um for it to become toxic and so when we think about toxicology we 28:12 can start to think about the factors that are really important there's individual variability medical conditions genetics age gender but 28:20 there's a number of aspects that go into the dose as well kind of the duration of exposure the amount the concentration 28:26 the route that we ingested orally or was it just on our skin how much did we absorb the frequency of exposure when it 28:33 comes to certain things like aflatoxins we can think about that as well all of these things are come together 28:39 and produce toxicity both individual and population levels 28:46 we can also think about things that are positive like you know uh Access to 28:52 Health Services access to a healthy environment um access to Geographic locations that 28:57 help mitigate some of these environmental toxins and from what we're talking about access to technology 29:05 from an environmental health framework and I like to think about asthma that we know that there's individual variability 29:10 in terms of who gets asthma based on genetics certain medical conditions or the allostatic load that someone has 29:17 essentially been immersed in during their life course there's also kind of 29:22 the need to minimize toxic exposures the dose of certain things like pollutants 29:28 the duration that people are exposed to them the frequency and the toxicity and 29:33 then we also know that it's important to maximize exposure to healthy environments access to healthcare access 29:38

to information access to environments where people can live without asthma triggers and these are things related to

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location do they have access to Green spaces do they have the mobility to get there but also aspects relating to

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certain social and structural determinants of Health to know whether or not people are able to afford things like humidifiers or do they live in

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public housing where mold exists and no one's really taken care of the uh of a 30:05

lot of problems that exist in in certain types of housing so we can adapt this framework towards

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information environments as well because there's a lot of psychological literature that's looking at individual

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predispositions in terms of Personality some of the cultural values that are associated with belief and

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misinformation there's a term that I really don't like but it's common in the literature about cognitive sophistication there's also just the

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individual agency that people have in terms of their media consumption habits we can also minimize toxic exposures and

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what does this mean from a misinformation perspective but how do we get in our information we know that

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certain types of information are stickier than others right if if you read something on a CDC website that

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takes work that's harder to remember than if you watch it in a tick tock video so the dose that's required to remember

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something you don't have to read it as many times if you're just watching it as a video versus if you're reading kind of

31:01

up to date or a CDC website so the duration the frequency and there are 31:06

certain memes um that tend to be more toxic our collaborators at Annenberg School of 31:12

communication Kathleen Hall Jamison and the factcheck.org group are have some preliminary data to suggest that certain

31:19

uh memes about the vaccines tend to be more toxic and spread with more

frequency and are stickier psychologically and those those include misinformation about the vaccines

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changing your DNA and your genetic makeup those are memes about uh vaccines 31:35

affecting fertility and those are aspects comparing how a claiming falsely 31:42

that the vaccines are more dangerous than covet itself and then finally we can maximize

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exposure to healthy information environments this means access to high quality information both in trying to

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help incentivize healthier media consumption habits but also structural 32:00

factors to ensure that people have access to these things to ensure that algorithms are promoting high quality

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information over the more toxic information and then this is also an issue of 32:13

healthcare access promoting access to health care and trusted experts survey 32:19

after survey shows that that people trust their primary care physicians but if they can't access their primary care

32:26

physicians they're getting information from more accessible sources and this is very important when we come when we

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start thinking about overall information environments so when we start to apply this model to

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things that we can do we can think about this from a sanitary perspective there's certain prevention uh techniques that we

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can that we can think about that are really important because I as we know like we didn't really get kind of

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epidemics of food safety under control until we made food safer and had a lot more regulations around food until we

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kind of started working on making sure our water was clean taking off the pump handle as as Jon Snow is famous for and

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then also you know including antibiotics and vaccines then we started to be able to work towards a an epidemic uh focused

model rather than everything seeming like a constant epidemic which is a little bit what it feels like now if

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you're working in the misinformation space so this means doing things like trying to reduce kind of other algorithmic

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approaches that help people convince brainwash themselves with the internet trying to avoid epistemic bubbles in

33:33

Echo Chambers this also means a building media literacy and digital literacy so 33:38

that people can use these tools but not necessarily be sucked on rabbit holes that make you start to believe that the

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Earth is flat this is also a particular focus on marginalized populations who have very 33:50

Real historic reasons to mistrust the government or mistrust kind of common 33:56

sources of trust trusted information um and and try to make sure that that 34:01

distrust cannot be leveraged to further so distrust an excellent example of this is the Nation of Islam who does who is

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very stridently anti-vaccine and has done a lot of work even partnering with 34:14

Children's Health defense to create anti-vaccine materials specifically targeting black communities in the

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United States on the basis of very real medical mistrust from a long history of 34:25

racial discrimination so there's a lot that we can do on this front as well and then finally ultimately there needs to be a lot of

34:32

content moderation this is going to be an essential component going forward 34:37

some of this has started to happen already where the National Academy of Medicine has come out with a report identifying credible sources of health 34:43

information on digital platforms and has developed some principles and these principles are actually being 34:49

incorporated into algorithms on YouTube so that it prioritizes information coming from the most credible sources

this is a start I would say this is necessary but very likely insufficient to start to get our hand around this

35:03

problem but as with any kind of environmental approach there's we're going to need a 35:10

conglomerate just a piecemeal approach attacking this from a number of different angles

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there's also aspects on the response side and what I mean by that is trying 35:20

to maximize exposure to healthy information this is a little bit of some of the work that we do with our

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infidemiologists there's also an argument that I make for screening for information environments

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at the point of care like we do for other social determinants of Health and then briefly I'll go into a little

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bit of discussion of you know some things that we can do as clinicians um what are some of the response

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strategies that we can have and obviously I'm not going to be able to go into that into too much depth but hopefully just to cover briefly that 35:50

here so I mentioned earlier about how networked health communication uh puts 35:56

all the stakeholders in the same room this can lead to a lot of miscommunication and misunderstanding because a word used in one environment a 36:04

word like septic for example means a something else in in amongst other communities and I think we saw this with

36:11

the pandemic when people were talking about a micron being mild and it was arguably mild from an epidemiological

36:17

population Health perspective but then people interpreted that as well it's going to be mild if an individual gets

36:23

hit and that was clearly not necessarily the case um our infidemiologists we see them as

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working in this space and I our infidemiologists we see essentially as the field epidemiologists for infodemic

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response where they are engaging kind of on a as a part-time part of their time

being kind of community embedded working in online communities as Liaisons between experts who have the information

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and their community they are doing community oriented motivational interviewing which is an

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adaptation of motivational interviewing that we are engaging in to adapt it to these online community spaces

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because motivational interviewing there's a lot of uh a lot of Empirical research showing that this is often some

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of the best ways to engage people to understand where they are on the spectrum of behavior change and if they

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are in a stage where you can engage them then working with them to understand kind of the barriers to resistance

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we also argue that infidemiologists are probably going to be most effective if they have a network where they can share

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information with other infidemiologists about what misinformation is circulating in their communities so they can share

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kind of effective responses to it and also share it up the hierarchy within the Public Health Community so that

37:41

people higher up the chain kind of can leverage resources necessary to try to 37:46

help Tamp down on epidemics of misinformation that seem to be essentially going viral 37:53

so who could be an infidemiologist we argue essentially any healthcare worker could community health workers GPS NPS

37:59

Public Health Department officials Specialists societies we've been working with the American physical society and

38:07

we've been working with um uh the American Board of internal medicine as well 38:12

um trusted Community leaders and potentially Someone Like You 38:18

so if this would be interesting to you please don't hesitate to get in touch we see our infidemiologists essentially

as mediators in this network's communication space translators ambassadors kind of there's a number of

38:31

different ways that you can think about the work that they do but essentially trying to help make sure that uh these

38:37

conversations in these in these Chambers where everyone is talking to each other to help make sure that misunderstandings

38:43

don't happen nearly as frequently so we we also make the argument that 38:49

it's important to screen for information environments at the point of care so these include questions like where do

38:55

you get your health information so the patient I had with ehlers-danlos syndrome this is a question I put to her

39:01

specifically and she walked me through kind of where she got a lot of her health information and it it revealed that she was getting

39:07

a lot of her health information from people that she thought very highly of because they had won this award or that

39:14

award or worked at some famous Medical Center um and what I did is I walked her 39:20

through kind of some of their profiles on quackwatch.com to show them show her 39:25

that that I I understand that you see these are trusted sources but but I'm I'm worried that some of the information

39:31

they they are promulgating might not actually be in your best interests so we 39:36

can ask questions about where do you get your health information how do you saw how do you decide what or who is

39:42

trustworthy how do you sort between good and bad information we as Physicians we don't just have

39:48

knowledge right because people can get Knowledge from Google what we have is we have a framework for making kind of

39:55

clinical decisions and our clinical decision making framework of pre-test probability likelihood ratio and

40:01

post-test probability is something that in the work that I've done with communities that uh that are suffering

from contested illnesses this is often one of the biggest misunderstandings that I find is that there's a certain

40:15

illusory truth effect by hearing things over and over and over in the epistemic 40:20

bubbles that they are sometimes existing in in these disease communities where they are sharing a lot of this

40:26

information um and it just gets absorbed it's not necessarily a conscious process of I'm 40:32

now going to believe this information but this is something that we as Physicians try to be very careful about

40:37

to decide between a good and a bad paper that is published in the medical journal that's something that we're trained to

40:43

do and this is something that we can have conversations with our patients not necessarily to go in depth on kind of

40:49

you know Journal Review or inviting them to journal clubs but just to to help them understand that there is a

40:57

difference between a good or a bad paper and that's an important aspect of of information literacy and science

41:03

literacy so the goal ultimately in some of these conversations is to understand someone's

41:09

individual predisposition their exposure to toxic information and their access to 41:14

high quality health information and I do make the case this is not something that every provider needs to do with every

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patient just like you know if you're working as a provider in a primary care clinic you might not necessarily have

41:25

the time to ask someone about their alcohol content but the people that you're working with the nurse or the M.A

41:30

might might screen for that and let you know when it turns out your patient who you might not have suspected is is

41:37

drinking 30 to 40 beers a week that's the kind of thing that you would want to know and then you put it on your list as

something to intervene in this is also something that we can start to do at the point of care and I talk a little bit

41:48

more about this in this commentary so what are some of the techniques that 41:54

you can use for communicating on contentious issues because they think this is something that is worrisome for

41:59

providers so first the evidence for motivational interviewing is very strong 42:05

um it the empirical evidence is primarily in the in the vaccine hesitancy space but there started to be

42:11

more and more uh a empirical uh papers to study this in other contexts related 42:17

to misinformation there's also the argument that we should acknowledge complexity and Nuance that's

42:23

usually something that our patients understand too and we can retain trust 42:28

even about extremely contentious political issues by emphasizing our role as a clinician 42:35

trying to work with the patient to figure out what's best for them in their unique circumstances this is what helps

42:42

us leverage the trust that people have in their providers and for more work on this you can read some of the work

42:48

that's done by our node gun Yar at the University of Sherbrooke he's done a lot of work on motivational interviewing and

42:53

vaccine hesitancy and Lisa Martin who's an OB GYN at Michigan who's done a lot of work not all of it published but a

43:00

lot of work looking at how providers can talk about the contentious issue of abortion even in situations where it

43:08

seems highly polarized so one other approach that the World

43:14

Health Organization has advocated is specifically trying to understand some of the un structures that people use in

43:22

science denial techniques and um patients that come into our clinics I think often not necessarily because they

are science denialists but because they are in circles where they're reading information online getting information

43:36

from what might be dubious sources there's a certain amount of adoption of some of these techniques and so we hear

43:43

them in the clinic and in clinical settings even if people don't necessarily recognize that these are

43:48

common anti-science tropes but we can start to hear them because you know 43:53

people say things like you know I prefer natural products or Farmers just out to make money monkey pox isn't a big deal

44:01

sometimes people say that or you know I heard the diabetes you know it's more the the medications are more dangerous

44:07

than the disease medications don't work for me government just wants to control you people get horrible side effects

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Gates is trying to track you and we can put these into categories where people are often worried about seeing larger

44:20

picture maybe it's the threat of disease maybe it's the idea that there might be Alternatives trust the effectiveness of

44:28

certain things and safety and we can put these concerns that they have in these 44:33

larger bucket categories and try to address those specific categories but 44:38

first we also need to identify the technique in which they're saying these uh concerns these can be things like

44:45

conspiracy theories sometimes there's selectivity cherry picking certain papers that kind of lean them towards a

44:52

specific perspective fake experts this is something that we often find in the anti-vaccine space with Wakefield is

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probably the the best example then there's also misrepresentation and false logic this is where our our role

45:07

as Physicians can help in the way that we think through clinical decision making we can walk people through our

thinking and see that there's a certain amount of false logic there's also sometimes impossible expectations

45:18

um I think I see we've seen this a lot with the vaccines where people talk about oh the vaccines don't work

45:24

um where the expectation was that that the vaccines were going to stop covet in its tracks and and covet wasn't going to

45:31

be an issue anymore it's like well they've saved many many lives um uh just because they're not super

45:38

effective at blocking all transmission does not necessarily mean that they are um uh they have failed so if we

45:47

choose a response to the technique and we choose a response to the topic this helps us design our answer

45:54

now there's obviously there's a lot more on this this is just a a very broad overview of some of the the tricks and

46:01

techniques that you can use in clinical settings more of this has gone into kind of in the report that the World Health

46:07

Organization wrote in their from their European office on best practice guidance on responding to vocal vaccine

46:13

deniers in public we have found this to be helpful not just for vocal vaccine 46:18

deniers in public but often in discussing misinformation in general even about other topics that have no

46:24

relationship to vaccine and even in one-on-one conversations so just to recap 46:31

our goal today was to to Define misinformation was to talk about how we we can move from message based to

46:37

networked health communication and how this requires moving from message based to environmental models of

46:44

information health and how ultimately this I think this can help us operationalize an information

46:51

environment framework to broadly address medical misinformation point of care 46:57

um with that um I I put my email address on screen I'd be more than happy to continue this

47:04

this discussion um with folks that want to get in touch and um I look forward to your questions

47:13

great thank you so much um and everybody feel free to put questions in the chat or raise your hand

47:19

if you um if you wish um Dr Del Rio I see you're hand raised

47:24

go ahead and unmute yeah thank you David that was great I mean my only question to you is you know your your premise is

47:31

almost like we Physicians are not spreading misinformation which is a solution when in fact we're frequently I

47:37

mean there's a group of Physicians not many but they're out there who are actually spreading this information who are the ones that are fueling this and 47:45

many of them have been uh you know they've been sanctioned by the awards the abim is looking into what else to do

47:51

but but I think we need to talk about what how to deal with colleagues that are that are spreading this information

47:56

and how what's the best approach there I completely agree

48:02

um I know uh the American Board of internal medicine and a number of other Medical Specialties have been talking about

48:09

um essentially revoking uh diplomats from very egregious spreaders of this information so that's one thing that's

48:15

been talked about um I also I've been there's a piece that I'm working on trying to publish right

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now that is talking about kind of when I mentioned how we got here there's a certain sociological aspect of how how

48:29

scientific facts are created and that tends to be a socially mediated process I think one of the things that we're

48:34

finding is a lot of Physicians are engaging in in debates and discussion on social media that are completely

legitimate scientific debates but the problem is those debates because they're happening in public can very easily get 48:48 co-opted by political actors and I think one of the things that we need to do as a profession is is 48:56 recognize when when the debate that we're having is happening in public because that is not necessarily 49:01 something like well debate is super important for science having having a debate in public about 49:08 scientific topics that are extremely uncertain and highly politicized does not necessarily lead to increased trust 49:14 in science and I would argue tends to increase uh misunderstandings and misinformation and is very easy for 49:22 someone a scientist that's just trying to have a scientific debate to be co-opted by political actors 49:28 I agree 100 thank you no agree as well um communicating Nuance 49:34 is something that I think that's really um difficult for the public to understand often at least seeing this in 49:41 my own family um Dr law yeah thank you Wendy and thank you Carlos I think you guys set me up well 49:47 for my question David thanks for being here um there you know as Physicians and 49:52 scientists there will always be uncertainty um and I find that many times the areas 49:58 not only of nuance but especially uncertainty are the places where misinformation really takes hold 50:05 um autism is a great example where I think families are looking for answers about what caused this problem and I 50:12 think we in the scientific Community can't answer that yet similarly in the early phases of the pandemic there was 50:20 so much unknown and uncertainty that we as a scientific Community didn't have scientific answers to and that then 50:27

leads to the um that that offers the opportunity for misinformation to really take hold so I'd love for you to speak a 50:34 little bit if you could on how you might recommend that we discuss the concept of 50:40 uncertainty with patients um perhaps in a way to help them help 50:46 build relationships where we can continue to have conversations about misinformation 50:52 um thanks for that question that this is a topic that I'd love to talk about because I think this is a crucial factor 50:59 that is not always addressed when we're thinking about why misinformation spreads and what we need to do to 51:05 counteract it the sociological literature on this is is mixed there's a 51:10 lot of different factions on this um briefly I'll just tell you about one 51:15 so uh so hofstede he was a sociologist in the 60s that looked at 51:20 um business cultures at IBM and he kind of separated cultural values that came out of 51:27 um the the hundreds almost 100 000 surveys that he did across 50 different 51:32 countries to separate out different cultural values um these are things like power distance 51:37 how important are hierarchies um uncertainty avoidance which we can think of essentially as a tolerance for 51:43 ambiguity and other aspects some of which sound really dated he talked about like masculinity femininity which sound 51:49 weird to us now but you could essentially think of as as a little bit of a you know stiff upper lip culture 51:55 versus a nurturing culture and there's a number of others uh there's a lot of other kind of cultural Frameworks 52:01 Schwartz has one there's a lot of other people that have different Frameworks but I like hofsted's because the 52:06 uncertainty avoidance in power distance have come up in a lot of of medical studies so mostly in Europe though and 52:14

this is is actually have been shown to be extremely important when it comes to antibiotic decision making because

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based on surveys that they've been doing for well over 20 years countries that have high rates of

52:27

uncertainty avoidance and high power distance have higher rates of antibiotic 52:32

prescribing antibiotic seeking Behavior by patients and antibiotic resistance 52:38

and the scary thing is this stuff is deep it generally kind of tracks along the Protestant Catholic line between

52:44

northern Europe being a lot more a lot more comfortable with uncertainty and having flatter hierarchies in southern

52:50

Europe having a much more hour distance kind of more rigid hierarchies and much 52:56

less tolerance of uncertainty now the challenge with this is if you're doing any sort of you know Behavior change

53:03

modification around antibiotic prescribing you need to be taking these 53:08

cultural factors into account there's also been some fantastic work that looks at these cultural differences between

53:14

Medical Specialties looking at how surgery tends to be on the spectrum of uncertainty avoidance and so it tends to

53:20

not follow antibiotic guidelines on the perspective of of both the uncertainty 53:26

avoidance and the relatively Rigid power hierarchies Within surgery asmita 53:32

sharani is a woman who who has written about these and I put 53:38

her name in the chat she's at University College London um so there's been a lot more social

53:45

science work on uh on this specifically at the intersection of antibiotic 53:51

prescribing but I think we can extrapolate to see that this is a larger problem in medicine in general and it's

53:56

a cultural one and so it's not necessarily the easiest to address one of the things that I try to do is is in

situations where I recognize there might be some uncertainty uh differences in terms of uncertainty tolerance between

54:11

my tolerance for uncertainty and my patience tolerance for uncertainty I usually try to find some way to offer

54:19

certainty even if that's certainty of process where someone walks into a clinic with with you know saying that

54:26

they have Lyme disease and they're coming with you know a a three inch binder of all the tests that they've had

54:32

previously and I I and a lot of of clear anxiety about their disease I don't 54:38

necessarily I try to be careful to not dismiss them as just being anxious or kind of having medically unexplained

54:45

symptoms but but they're kind of can't be reassured there's a lot of pejorative terms that are in the medical literature

54:51

for this type of essentially what I would argue is a discrepancy between the physician's tolerance of uncertainty and

54:57

the patient's tolerance for uncertainty and then I start to work with them to try to essentially walk them through

55:02

what I'm going to do to make sure that I look under every stone and I am going to 55:07

be I'm going to know your chart better than anybody else and that doesn't mean that I'm going to find an answer but it

55:12

does mean that that we're going to talk to everyone that we need to talk to to try to get as close to an answer as we

55:18

can in some situations patients find that comforting in other situations not 55:23

having that diagnosis is still very discomforting for patients um and that's something that we can we

55:29

can work with but at least we've done what we could to try to find as much certainty as possible yeah thanks I think that term certainty 55:36

of process is helpful and I we I think we've definitely all seen that at least 55:41

if we can't provide the scientific answer a certainty of process and and 55:46

and building trust through that um is is one Avenue to pursue yeah thank you so much 55:53

there are several great questions in the chat that we won't have time to get to all of so this is going to be sort of

55:58

the rapid fire round um so um our residents are asking a couple of things 56:04

um do you have any guidance you talked really about the infodemiologists being what I almost call what I think of as

56:10

trusted Messengers uh do guidance though on how to approach medical mistrust from 56:15

marginalized groups when you're at the bedside you don't have that Community person that is there to sort of help you

56:21

and um also from them um uh so not only at the bedside but

56:28

then how about with open notes and the communication of uncertainty there sure 56:33

thanks I'll actually start with the open Notes question because the short answer that I would say is I don't know how

56:39

this is going to affect um what I would say is so you know Facebook instituted its share button in

56:45

about 2011 2012 and that turned information consumers into information producers right and we only started to

56:53

see the knock-on effects of that well after that Twitter introduced its retweet button around the same time so

56:59

it completely changed the network architecture of how information was transmitted what we've seen is open Notes is relatively new what impact this 57:07

is going to have I can't be certain but I'm concerned because it's it's changing the network architecture of how

57:13

information is transmitted um and so I think we're we have yet to see the full impact of what OpenNotes is

57:18

going to be doing um on the question of um how we can kind of engage a lot of 57:26

the work that I've done with Muslim communities um I've before the pandemic hit I I did 57:31

a lot of global Health work a lot of work with refugees and a lot of that work um when I would be working with Muslim

communities and found myself at an impasse I would I would often ask directly I would say is is there someone

57:45

that you trust that you talk to about some of the medical decisions that you make sometimes that was another family

57:50

member sometimes that was in Imam and I would say would it be possible to bring them into this conversation and and

57:57

usually I find that a very helpful uh place to go it's not always possible 58:03

um it depends on kind of the level of trust that you have kind of at that time this is something that's definitely easier if you have an ongoing 58:08

relationship with a patient than as a hospitalist but it's something that I I try to ask that question directly and it

58:15

and acknowledge the fact that like they have reasons not to trust me they just met me but let's try to have a

58:21

conversation and bring the people who influence you into the room so we can at least kind of put all of our information

58:26

on the table and and try to discuss how we're going to make this decision is this going to be a values-based decision

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is this going to be essentially an identity based one or is this one that we're going to make with the best evidence that we have available

58:39

because that's my job I can bring the evidence to Bear but sometimes you need the values person in the room

58:46

that's a that's a really nice thought um we are at the top of the hour and so I think we have to close sorry doctors

58:53

Dressler and Henry who also had fantastic questions um in the chat but thank you so much Dr

58:58

scales this was a a really interesting sort of approach dive into thinking 59:04

about this problem of misinformation I I'm afraid we'll never get the genie back in the bottle but uh but it at

59:11

least gave us some ways to think about um moving forward

thanks again for having me it was a pleasure to be here please don't hesitate to get in touch if you have any questions 59:21 great thank you