15:58:05 >> With that, if anyone has any questions or comments as we get ready to go into our full program at 4:00, please feel free to submit them via Q and A. If you're having any issues with your interface or participation, and we can try to address them throughout the course of today's conversation.

16:00:45 With that we'll give folks another two minutes or so before we begin our presentation, and we want to thank you all for joining us for the first of our four sessions for the health equity and ethics series. Thank you. .

16:01:10 >> I'd like to welcome you to our inaugural series on health equity and ethics. We're starting promptly because we have a very ambitious agenda today. We will be continuing to welcome people into our space, but I'm going to start by just orienting you a little bit to what we plan to do not OENLT today but in our health equity series.

16:01:21 So first let me start by introducing myself. I'm Kristi Kirschner and I'm the emcee or moderator for the first panel today. And I'm bringing to this role several hats.

16:01:33 So one of the things you'll notice as we introduce ourselves to you that we're thinking intentionally about who we are, what roles we bring that inform our experiences and our perspectives.

16:01:58 I'm bringing the perspective as a physician who's cared for people with disabilities, a teacher, somebody who has worked in the field of ethics for a number of years. I'm also bringing the perspective of being an advocate for social justice and a caregiver for an 86-year-old mother who's had lots of issues during this period of COVID.

16:02:24 So that's who I am and I want to tell you that as we move through this, we're going to be recording the series. You all had a chance to acknowledge that on the registration and hopefully you had to acknowledge it when you came into the room. But we'll be recording the session. It will be posted after the fact. And we'll give you a little bit of orientation to the Q and A.

16:02:28 So you can decide if you want questions to be anonymous.

16:02:32 So just a word about the series.

16:02:44 This is the project of a number of people across the University of Illinois at Chicago, different schools, colleges, different faculty members, and community members.

16:03:12 And we came together with the idea that we wanted to develop a different kind of format for sharing stories about injustice, invisibility in health care, to try to understand the issues of health and wellness from multiple perspectives but not just to be descriptive. We want to be action oriented. We want to focus on real life solutions that are actionable, that build on community strengths,

16:03:16 that are guided by our ethical values and informed by our shared wisdom.

16:03:31 So in terms of our general structure for this series, each panel is constructed essentially the same. The story is the heart and soul of the entire series, and we consider it the heart and soul of health care.

16:03:46 We're going to hear the story from the perspective of somebody whose life has been deeply touched by COVID. It's going to be told as a facilitative dialogue with somebody who has at least walked that journey partially with them.

16:04:18 We then have different perspectives on the panel. We have somebody who can speak to ethics or health professionals. After we've heard the facilitated story, we'll innovate them to react or respond to what they've heard, and then we want you to engage with us to submit your questions and to -- we're going to share with you at the end how we hope your engagement will continue throughout the series.

16:04:30 So to get off and running today, we have these various panelists. I will introduce each in turn as we hear from them.

16:05:04 But I'm going to start with Dr. Rana Hogarth. And she brings to us her perspective as a historian, a teacher, a parent, and an advocate to the discussion. We are deeply grateful for her involvement today. She has to leave us in 45 minutes, so we're going to turn to her to set the stage for ground our discussion for a facilitated dialogue and then we'll come back to her at the end.

16:05:10 >> RANA HOGARTH: Thank you very much for this very generous introduction and for letting me -- allowing me to participate.

16:05:26 What I would like to do today is to just provide you with some historical framing for conversations about health inequity and anti-Blackness in medicine. I think it's always a good idea to think about the history and think about how that can inform us today.

16:05:33 So let's move onto the next slide. And I will start with a kind of a story with a quotation.

16:05:57 A fact from Dr. Moseley of the indifference in which Negroes submit to the operations in surgery in the West Indies. Even in this country the Negroes have been observed to handle fire without emotion and the not suffering from it like white people. This is a quote from Benjamin rush from the late 18th century.

16:06:03 As a historian I feel I must be transparent so you will see in a moment the actual image of his text, where it comes from.

16:06:41 These are indeed his lecture notes as we'll see in just a moment where I went to the archives and I kind of looked at what this physician had to say, specifically highlighting, as we'll see, what Dr. Benjamin Moseley says, and this is essentially a case of two well-known physicians making comments about Black people's bodies. And as you can see, Dr. Rush is making the claim that Black people tend to not suffer from pain as much, that they are insensitive. And he said he's hearing this from.

16:07:00 And as we'll see, this Dr. Moseley actually wrote a treatise which Benjamin Rush is sort of referencing. So as a historian, I follow the trail, I follow this kind of information and think about how these damaging ideas about differences and suffering based on race emerge and how they sort of circulate and propagated.

16:07:26 So if we move to the next slide, we'll see that what I want to do here is to foreground a racial (inaudible) of African Americans suffering from disease. And one way to do that is to tell a story about yellow fever. And as we'll see, this was a disease that terrified many in the 18th century. A number of treatises were written about it. And an observation that I found in my research was that

16:07:32 yellow fever, at least according to some of these physicians, appeared to attack individuals based on their race.

16:08:06 Physicians would say things that whites or unaclimb advertised newcomers to the Americas were viewed as most vulnerable to yellow fever where Black people were virtually immune. And these views led to erasures of Black people's suffering from the disease within the historical record. And you'll see this is the very well known essay from the 18th century where a very well known physician John limeing says quote, there is something very singular in the constitution of the Negroes

16:08:09 which renders them not liable.

16:08:25 Which is a simple beginning of a very long history in which African American suffering is either dismissed or is regarded as something as other, as peculiar and is distinct. And this is something that I find that has very long and deep roots in American medicine.

16:08:57 So we move to the next slide. You'll see that Dr. Benjamin Rush who I started my story with also believed in this idea of innate Black immunity yellow fever. In fact during a major yellow fever EP chem I can in Philadelphia in 18223 he after I hadly read about yellow fever, and actually convinced members of the free African society of Philadelphia to stay behind and help with the epidemic which they did do.

16:09:22 He wrote to Richard Allen, a very well known free African American reverend and said will you stay behind and bury dead and nurse the sick and he agreed. The problem of course is African Americans are not immune to yellow fever. Any immunity would have to be acquired. There was no racial immunity. And now Rush does admit his error.

16:09:41 He says I was led to believe that the Negroes in our city would escape it. In consequence of this belief, I PUSHD LISHD the extract from Dr. Lining's history of yellow fever as it had four times appeared in Charleston in South Carolina. If you think about it, that's precisely what Benjamin rush was referencing.

16:10:02 Another physician, but rush realizeed that he was wrong about Black immunity to the disease. Nevertheless he still felt that there were racial differences in suffering. And he saw these differences, and he says, quote, the disease was lighter in them than in white people. Rush continued, I never met -- I met with no case of hemorrhage in a Black patient, end quote.

16:10:09 Yellow fever happens to be a hemorrhagic disease and so he's saying they don't suffer as much.

16:10:47 As we'll see, African Americans most certainly responded to these kinds of claims about their bodies. And this is an excerpt that I showed to you. This is actually written by Richard Allen and axel Jones, two African American men residing in Philadelphia and they note what was said about Black people's bodies. And they say even to this day, a generally received opinion of the city that our collar was not so liable to the sickness as the whites. We hope our friends will pardon West Indi t.

16:10:53 Happy would it have been for you and much more so for us if this observation had been verified by our experience.

16:11:12 So as we'll see, this is from their account of the yellow fever. I bring this to you simply to show you the African Americans most certainly pushed back against damaging claims about their bodies. This attempt of erasing their suffering from disease.

16:11:21 So if we move to the next slide, we will see that this kind of view of African American bodies is distinctive as other continues on into the 19th century.

16:11:31 And this is very clear when we think about this section and medical education in the United States in the 19th accept century.

16:11:53 African Americans both free and enslaved were subject to abuse, experimentation and neglect of physicians. They made up a population that historians note were both visible and invisible and that is to say they were EESZidentifiable by their skin color, their status, but they had no legal recourse. They were invisible in the sense that they could not push back in any kind of legal way.

16:12:02 Their bodies were disproportionately used as anatomical teaching material and they were disproportionately used for dissection.

16:12:14 African American cemeteries were more likely to be disturbed by body snatchers and grave robbers. And again just to be very clear here, there's no way to stop medical schools from preying upon their bodies.

16:12:31 So this is the sense of African Americans' bodies being sort of targeted and already seeing that there were -- that they were innately different but now we're seeing an attempt of sort of PRE days on their bodies for medical knowledge and to train future physicians.

16:12:57 So if we move to the next slide, I want to offer you yet another quote and this is actually from the dean of one of the first continuously operating medical schools in the deep south. This is the medical college of South Carolina, which opens its doors in 1824. And just to give you a clear sense of what I mean when I say that medical schools and preyed upon African American bodies, this was in the faculty

16:13:13 meeting minutes. Quote, no place in the United States offers as great opportunities for the acquisition of anatomical knowledge, subjects being obtained from among the colored population in sufficient number for every purpose and proper dissection carried on without offending any individual in the community.

16:13:30 These impediments which exist in so many other places to the prosecution of this study are not here thrown in the path of the student. In addition, the southern student can nowhere else receive correct instruction on the diseases of his own climate or the peculiar morbid affections of the colored population. End quote.

16:13:51 It's actually a very alarmingly clear, exactly what the dean means of this particular quotation that because people feared having their bodies dissected, he says we don't have to worry about that. We will simply use the bodies of African Americans. It's a very clear predatory stance towards the African American community here in Charles ton and South Carolina.

16:14:02 And we see here again this hinting that medical students will be able to see so-called diseases of African Americans, the so-called colored population.

16:14:23 So if we move to the next slide, we might say to ourselves, okay, well, that was all in the past and we don't have to worry about that kind of behavior, those kinds of long headed views. And I would say we might want to consider just a moment. And by that I mean we still do rely on these assumptions, perhaps they're more subtle, about innate racial difference.

16:14:41 We can think, for example, of the use of race correction in clinical algorithms. I'm certainly not the first person to notice this. You will actually find that in the new England journal of medicine, there are a number of pieces that have come out that have basically said maybe clinicians need to reconsider the use of race correction.

16:14:53 And so race correction is something that you might see in the use of a spirometer to measure lung capacity. You might also see this in the case of nephrology, particularly in calculation of EJ afar.

16:15:17 As you can see highlighted here, this is where we see adding a points to the assessment of kidney function if the patient is identified as Black. And so this has a lot to do with saying okay, well, how healthy do the kidneys seem. If you are simply adding points to patients who self-identify as Black, what you might be doing is saying that they have higher kidney function than they really do.

16:15:22 So the issue is to think that this race correction might need to be reconsidered.

16:15:54 As we can see, you know, looking at other cases of sort of how race is being misrepresented, again in the new England medical journal of medicine, if we see again, there's another reference to the EGFR where you have -- as we can see in the particular -- I think it's blown up. There's a highlighted piece here where the authors say what do we do if you have a mixed race patient where they may self identify as Black in one circumstance

16:16:11 and they have points added to their kidney function and then if they self-identify as white and they don't have points added, what we see here is the imprecision of this idea and the fact that we are putting -- investing so much on this concept of race that it means something biologically.

16:16:14 And this still continues in medical practice today.

16:16:19 So if we move on, we can say to ourselves what should we make of this history.

16:16:46 Well, again, it's really not all just buried in the past. The 2016 study by Hoffman et al. On racial bias and pain assessment published in the proceedings of the national academy of sciences of the United States suggested a number of troubling findings. So we can see one of the findings was, was that many white lay people and medical students and residents hold fuel beliefs about biological differences between plaques and whites.

16:17:01 Study also revealed racial bias in pain dissection is treated in pain treatment. Finally it showed beliefs between biological differences between blacks and whites continue to shape the way that we perceive and treat Black people.

16:17:16 And we see that there are certain beliefs, for example, that these surveyed residents had, beliefs that Black people have thicker skin than do white people or that Black people's blood coagulates moreicthan white people's blood.

16:17:29 So what we are seeing here, essentially these are beliefs coming from 2016 so this is why as a historian I say yes, these things happen in the past but let's not quickly say it's not our problem anymore.

16:17:39 As you can see from Hoffman et al. Study, which is I think really useful, especially thinking about pain assessment, we still have to reckon with these problems today.

16:18:05 So we move to thinking about COVID. As you can see highlighted here, there's a concern about vaccine hesitancy, right, where people say, well, we have these vaccines. We want everyone to get access, but we are noticing hesitancy that is falling along racial lines. And it's highlighted here in terms of which patients or which groups of people are more mistrustful.

16:18:29 It's about something like well, 60 percent of Americans say they will definitely or probably get COVID-19 vaccine, only about 42 percent of blacks will do so compared to 83 percent of Asians, 63 percent of Latinx and 63 percent of white adults. And as we can see, this is coming from the Pugh research on center survey which was conducted in 2020. So this is again fairly recent information.

16:18:42 But I think in addition to being aware of this vaccine hesitancy, we also have to be aware of the problems of vaccine rollout and sort of how health inequities and structural racism play a role.

16:19:10 So thinking more locally, as we can see from information taken from Chicago, and that is to say thinking about the vaccine rollout here and how it's actually highlighting already existing inequality. So there's a particular reference to the issue of a pharmacy deserts. The idea that, well, we'll roll out the vaccine and we will ensure that the vaccine distribution will take place in pharmacies.

16:19:25 But as we can see, that in certain places in Chicago, particularly in the west and south sides, we are seeing places that are so-called pharmacy deserts, where you only maybe have independent smaller pharmacies which are not taking large doses of vaccine and able to distribute them.

16:19:52 So when you say, okay, we'll just put it through pharmacies, what you're doing is (inaudible) neighborhoods who have been historically who do not have pharmacies anymore, now it becomes quite a challenge for residents to say howget to the nearest pharmacy. Can I take one or two buses, what could have been five or ten minutes for someone else then becomes something of a much lodger or perhaps inconvenient situation

16:20:05 based on this inequity and based on the structural racism that has created these kind of enclaves within Chicago. So this is something I want us to be aware of when we think about the history but also about our current problems.

16:20:32 So if we move onto the next slide, I basically want us to consider a couple of points. One we should recognize how medical education and discourse has either explicitly or implicitly assumed Blackness to be PE KULG I can't remember. We should also consider how assumptions and subtle references to innate racial differences still linger in clinical settings and medical discourse and indeed public health messaging.

16:20:41 And I hope we will recognize the role that structural racism continues to play in access to health care in addition to all these things we must grapple with.

16:20:51 And finally I would like to say we really must listen to what community of color say about their experiences in accessing care.

16:21:02 Thank you.

16:21:06 >> Kristy, you're muted right now.

16:21:30 >> KRISTI KIRSCHNER: I'm sorry. Thank you, Dr. Hogarth. That was an amazing tour of a very extensive history. And we would like to think you for sharing your expertise with us. And we hope that you'll have a chance to come back and give us a little bit of thought about the narrated -- or the facilitated dialogue we're about to hear.

16:21:56 So we are going to turn to the story now that Ms. Army Stewart is going to share with us. And I'm going to start by introducing Ann Jackson who will be facilitating the dialogue with Miss army Stewart. And I have to tell you I'm really thrilled to be able to introduce her. I've known her for several years, and if you haven't met her, she's a force to contend with.

16:22:17 I also think she's a true bell weather for the project that we're engaged in. She has talked about the need for a different kind of health ethics paradigm that we need to focus more on social justice, that we need to attend to the story. So I can't think of anyone that's better situated to lead off this panel.

16:22:32 In terms of how she identifies herself, she describes herself as a learner, a neighbor, a teacher, a caregiver, an advocate, and a friend.

16:22:43 So with that, I'm going to turn it over to Dr. Ann Jackson and let her introduce Miss Army Stewart.

16:23:12 >> ANN JACKSON: Good afternoon, everyone. And Kristi, thank you so much for that very kind introduction. I hope that my work is worthy of those kind words. And it is my high honor and pleasure to introduce to our community a very esteemed person that I've come to learn about and to love and her name is Miss Army Stewart.

16:23:16 Miss Stewart, may I ask you to please introduce yourself to our group?

16:23:24 >> ARMY STEWART: Good afternoon, everyone. My name is Army Stewart, and I live in the Morgan park community.

16:23:30 >> ANN JACKSON: And would you tell us a little bit about your life before the pandemic?

16:23:51 >> ARMY STEWART: Before the pandemic, well, things were going along what I call normal, although I had two childrens here that I was the caretaker of. One didn't live with me. And I did, you know, the cooking, the cleaning, the washing, and you know, for my two childrens that lived here.

16:24:02 >> ANN JACKSON: So Miss Stewart, just to be clear, when you say your two children, may I ask you your two children, how old were they? Are they?

16:24:15 >> ARMY STEWART: Michael was 61. Carol was 60, and Bernard, he was 63 or 4.

16:24:21 >> ANN JACKSON: Okay. And so two of your children, two of your adult children lived with you, and you were their primary caregiver.

16:24:22 >> ARMY STEWART: Yes.

16:24:26 >> ANN JACKSON: And you were their primary caregiver because?

16:24:33 >> ARMY STEWART: I -- I was their mother, and that was, you know, what I had to do to take care of my childrens who were ill.

16:24:43 >> ANN JACKSON: Okay. So your children had health conditions. Can you tell us a little bit about them?

16:25:08 >> ARMY STEWART: Carol was diagnosed with breast cancer, although she was up and about. And Michael, he suffered brain damage in 2003, which he was able to function and do normal things. But in the last year, he was diagnosed with dementia. It came on because, you know, of the brain damage.

16:25:23 So I had to do everything for him, you know, sing to him -- seeing to him, eating properly. He was a diabetic. And it was out of control due to when he was able to do for himself, he wasn't taking care of himself.

16:25:35 So I had to manage, you know, to try and fix his food, you know, things that was healthy for him, right, and keep, you know, that diabetes in check.

16:25:37 And I had to do everything for him.

16:25:39 >> ANN JACKSON: So --

16:25:44 >> ARMY STEWART: Carol was able to do some things for herself.

16:25:59 >> ANN JACKSON: And did you have any support coming into the -- into your home in terms of community workers, or are you guys participating in any programs? Were you being paid as a respite worker for any of this?

16:26:03 >> ARMY STEWART: No, I wasn't paid for anything that I did for my children.

16:26:14 >> ANN JACKSON: Okay. And can you tell us, so this is January, February of 2020, and when the pandemic occurs, how does your life change?

16:26:44 >> ARMY STEWART: Well, when Michael, you know, he became, I guess, nonverbal. I really didn't know what it was, you know. I didn't know anything about, you know, the virus or anything. But discovered later on, you know, that that's what had changed his life, what he had contacted the virus. Although he didn't go anywhere without me taking him. But somehow it came into the house, the virus.

16:26:45 >> ANN JACKSON: Okay.

16:26:48 >> ARMY STEWART: So it affected him badly, you know.

16:26:59 >> ANN JACKSON: And can you tell us a little bit about what happened to Michael? How did you learn that he had COVID and then can you tell us a little bit about how you began to seek care for him?

16:27:20 >> ARMY STEWART: Well, he had changed, you know. He had stopped eating, and I would fuss at him. You know, you're not eating your food. You've got me doing this and that, not knowing, you know, that he was as ill as he was. And I was doing everything to try and, you know, get nourishment into him.

16:27:27 And then he wasn't getting any better, so I -- I said, well, he's got to go to the hospital.

16:27:55 So I called paramedics, and they came, and they looked at him, and they talked. And they said, well, if he goes to the hospital with the pandemic going on, they're not going to do anything for him. And you won't be able to see him. So they talked and talked -- I said okay, then. Well, just leave him here then. We'll do the best we can. It wasn't getting any better.

16:28:20 I called the paramedics again. And they discouraged me the second time. Okay. No better. I called the paramedics the third time, told THIM the same thing. Well, you don't know how dementia works. Dementia works this way and it works that way. I said, well, maybe so, but take him to the hospital.

16:28:31 >> ANN JACKSON: I'm sorry to interrupt you, but can you just help me to understand, these three incidents with emergency medical care occurred over a what time span?

16:28:33 >> ARMY STEWART: A week and a half period.

16:28:37 >> ANN JACKSON: Okay. Week and a half. Okay. I'm sorry to interrupt.

16:28:50 >> ARMY STEWART: And they did take him in. I followed -- well, I didn't follow the ambulance, but I made it to the hospital as quickly as I could. And they had, you know, put him in the emergency and all of that.

16:29:04 And when I you know, went in, by him not being verbal, I had to let the person at the desk know that he wasn't verbal so they went back and told, I guess whomever was in the emergency room.

16:29:19 So the nurse came out and talked to me and she was very complimentary. She said, oh, you're taking such good care of your son, you know. And she was getting the information and stuff that he needed, that they needed for him, you know.

16:29:27 And so she told me, you know, well, I could leave, you know, and anything that happened, they would call me.

16:29:35 So I called every day to see, you know, how he was doing.

16:29:49 The one thing I didn't like about this hospital, they were -- you know, when I would call, whoever would come to the phone, they act like they didn't want to be bothered, well, he's this, he's that. And they weren't very friendly, you know.

16:29:58 >> ANN JACKSON: Okay. And how -- and when you took -- when you took Michael to the hospital, how long was he in the ER before he got a room?

16:30:01 >> ARMY STEWART: He was in there a whole week before.

16:30:03 >> ANN JACKSON: He was in the emergency department.

16:30:03 >> ARMY STEWART: Yes.

16:30:06 >> ANN JACKSON: For one week before he got into a room?

16:30:07 >> ARMY STEWART: Yes.

16:30:11 >> ANN JACKSON: And then after he got into a room, what happened to him then?

16:30:32 >> ARMY STEWART: Well, I still wasn't able to go and see him, but I called every day. Then the doctor called me and I guess it was one of the nurses and things -- she was very sweet, you know. She said, well, we're going to pray for him and this, that and the other. And the last day that I called the -- I guess it was a nurse told me, well, he's not responding, you know.

16:30:40 And the different things that they wanted to do, they would always call me and ask was it okay to do that. And I would tell them yes.

16:30:51 But the ICU, when he got there, everybody I talked to, they were very pleasant and, you know, had attitude that they cared, you know.

16:30:55 >> ANN JACKSON: Well, that's wonderful. And so what was the outcome for him? What --

16:31:17 >> ARMY STEWART: Well, they wanted to do -- they were getting ready to do a treatment on him, and they weren't able to do whatever they were getting ready to do, so they called and told me that -- and they were going to try something else. And they were call me or I would call them, you know, to see what was going on.

16:31:22 And they would give me the information, you know, that I was seeking, you know, about his condition.

16:31:23 >> ANN JACKSON: Yes.

16:31:29 >> ARMY STEWART: But in the ER, the peoples, they came to the phone, they weren't pleasant at all. Like they didn't want to be bothered.

16:31:35 >> ANN JACKSON: So then for Michael, though, what was the ultimate outcome of this?

16:31:41 >> ARMY STEWART: Well, Michael ended up, he passed away April 17th of 2020.

16:31:43 >> ANN JACKSON: After being in the hospital for --

16:31:44 >> ARMY STEWART: A week and a half.

16:31:50 >> ANN JACKSON: A week and a half. And seven of those days, he was in the emergency department not in a room.

16:31:52 >> ARMY STEWART: Uhm-hmm.

16:31:57 >> ANN JACKSON: And from what you told me earlier, he went from the emergency department to ICU, is that correct?

16:31:59 >> ARMY STEWART: Yes, that's correct.

16:32:10 >> ANN JACKSON: Okay. And I see you have other family members represented in this collage, and you mentioned your daughter Carol. So can you tell us a little bit about Carol's story?

16:32:27 >> ARMY STEWART: Well, Carol, she was diagnosed with breast cancer, and she was a patient at -- she was at University of Chicago. So she had came down with symptoms, you know, of diarrhea and whatever.

16:32:41 So she was going back and forth to the hospital, and they said she had pneumonia. And they -- you know, they would send her -- she went there three times, and they would send her back home, you know.

16:32:47 >> ANN JACKSON: So in a day. So she would go down there with symptoms, they would treat her, and then she'd come back home.

16:32:50 >> ARMY STEWART: Yeah, she'd come back home.

16:32:52 >> ANN JACKSON: And this went on three times.

16:32:53 >> ARMY STEWART: Three times.

16:32:55 >> ANN JACKSON: And then what happened.

16:33:21 >> ARMY STEWART: The last time they kept -- when they sent her home, they sent her home the second time with oxygen. And then a nurse -- you know, they had a nurse coming, you know, I guess to check the oxygen level or whatever. And the Saturday morning that the nurse came, well, I guess she saw something that shouldn't have been, and she left and then they called back and said that for her to get to the hospital immediately.

16:33:29 So her granddaughter was here, so she took her to the hospital but she never came home again.

16:33:31 >> ANN JACKSON: She never came home.

16:33:50 >> ARMY STEWART: I talked to her every day, you know, on the phone, and I thought she was doing good. But then she told me one day, she said, mama, I'm getting scared, you know. So I said, oh, you're going to be all right. You know, she's telling me what she wanted me to cook when she got home and I just never expected this, you know.

16:33:52 >> ANN JACKSON: You never expected to lose her.

16:33:53 >> ARMY STEWART: Yes.

16:33:59 >> ANN JACKSON: And you lost her after her hospital admission, and she was in the hospital for a period of how long?

16:34:01 >> ARMY STEWART: She was in there almost a month.

16:34:14 >> ANN JACKSON: Almost a month. Okay. And then if you don't mind, may I ask you to continue your course? Can you please tell us more about your other family member that was impacted by COVID?

16:34:43 >> ANN JACKSON: Oh, yes. My oldest son, he -- he had a -- I guess you would call a respiratory. He was overweight. And he came down with the COVID, you know, didn't know -- you know, because he was on dialysis. And his wife -- he was on his way to dialysis that morning, and when she went out to go to work, he was still sitting there in the car.

16:34:55 And so she said something is not right here, so she called the ambulance. And they took him to a St. Bernard. They live in that area.

16:35:02 And he was there for awhile. And I didn't even know he was in the hospital because he told everybody don't tell me.

16:35:05 >> ANN JACKSON: Because he already had two losses --

16:35:17 >> ARMY STEWART: Yeah, and he didn't want to worry me. So when I did find out, I called him and talked to him and he said mama, I'm going to be all right, but I don't like this hospital. I don't want to be here, you know.

16:35:20 So finally he left, you know. He --

16:35:23 >> ANN JACKSON: He discharged himself.

16:35:27 >> ARMY STEWART: Yeah, he discharged himself and went to Christ.

16:35:29 >> ANN JACKSON: Went to another hospital for care.

16:35:30 >> ARMY STEWART: Yeah, for care.

16:35:35 >> ANN JACKSON: And was that going to that hospital, was that more helpful for him?

16:35:42 >> ARMY STEWART: Well, he was more pleased, you know, at Christ than he was at St. Bernard.

16:35:47 >> ANN JACKSON: Okay. And I ask about the ultimate outcome for him?

16:36:10 >> ARMY STEWART: Well, they were giving him dialysis. You know, they had called his wife, and she was there. They let her in. She could see him, you know, in the facility -- you know, where they were giving him dialysis, and he stopped breathing, you know, when he was getting dialysis. But he wasn't diagnosed with COVID, you know.

16:36:16 >> ANN JACKSON: So Miss Stewart, you're telling us that you've lost three adult children.

16:36:17 >> ARMY STEWART: Yes.

16:36:24 >> ANN JACKSON: In the last -- since the pandemic began, you lost children from April to December?

16:36:26 >> ARMY STEWART: To September.

16:36:28 >> ANN JACKSON: To September. You lost three children.

16:36:29 Jack.

16:36:31 >> ARMY STEWART: Uhm-hmm.

16:36:54 >> ANN JACKSON: I can't even begin to imagine what that must be like, and I -- I can only tell you how grateful we are that you are sharing this story. But I have to ask how -- how do you -- how have you cared for yourself? Were you -- how have you been able to care for yourself in the midst of all of that?

16:37:25 >> ARMY STEWART: Well, you know, it's through my church. If I hadn't had my church, I don't know what would have happened to me, you know. My pastor, he was very -- you know, he did the eulogy for all of my children and he was concerned about how I was getting along, called me. The church members called me. And I was very active in the church. So that kind of kept me, you know, my man from

16:37:31 although -- my mind from -- although every day I think about them.

16:37:43 >> ANN JACKSON: Well, so in their passing, how were you able to celebrate their lives? Were you guys able to have funerals for them? Were you -- how were you able to celebrate their lives?

16:37:57 >> ARMY STEWART: Well, Michael, when he passed, they weren't doing anything. He just mostly had a grave side, you know, at the funeral home. It was visitation. And then onto the cemetery. You know.

16:38:13 For Carol, they were able to do a small funeral for her, but, you know, with the social distancing. But it was a limited number of people that could go into the church.

16:38:15 >> ANN JACKSON: Yes.

16:38:24 >> ARMY STEWART: And it was the same with Bernard. Same thing, social distance, X number of peoples were allowed in the church.

16:38:25 >> ANN JACKSON: I gotcha.

16:38:34 So how were you able to attend three -- how were you able to carry that and to attend your children's funerals?

16:38:48 >> ARMY STEWART: I did not attend any of them. My granddaughter, Shakara, she was the last funeral I went to and I went to the doctor to get medication to see me through that.

16:38:51 But my three childrens, I just could not go.

16:39:04 >> ANN JACKSON: Okay. Wow, wow. Well, now we're in a new season, and I hope you're going to find some joy in this new season that we find ourselves in.

16:39:12 So now that we have a vaccine, have you been able to become vaccinated yet?

16:39:16 >> ARMY STEWART: I've had my first shot and I get my second one in the next two weeks.

16:39:24 >> ANN JACKSON: And what was it like for you to sign up for a vaccination? Was it easy to do.

16:39:38 >> ARMY STEWART: First I had signed up at Walgreens but they never called me. Well, they haven't called me to this time. But my alderman's office called about they were doing testing on March 23rd, and I signed up immediately for that.

16:39:44 And I was able to get, you know -- to get my first innoculation.

16:39:49 >> ANN JACKSON: So you were able to make your appointment object the telephone?

16:39:50 >> ARMY STEWART: Yes on the telephone.

16:39:54 >> ANN JACKSON: Could you have done it on the computer if you needed it.

16:39:57 >> ARMY STEWART: No, I'm not computer literate.

16:40:11 >> ANN JACKSON: Okay. Do you think now that you've had -- there's been a little span of time, do you think that anything could have been different in the care that your children received that could have resulted in a different outcome?

16:40:28 >> ARMY STEWART: Well, I think if we had had more information on the virus, you know, knowing what it really was, perhaps, you know, I could have acted more quickly, you know. But not knowing what it was, you know, I didn't really know what the virus was.

16:40:33 Although I had heard about it, but didn't totally understand it, you know.

16:40:50 >> ANN JACKSON: Well, how did you -- in general, how did you perceive your -- the care that your children got? Did you perceive that they got quality care? Did you feel as though they were listened to, that your voice was listened to as an advocate for them?

16:41:21 >> ARMY STEWART: Well, I'm going to tell you the truth. No, I didn't -- wasn't allowed to go to the hospital. But, you know, telephone communications, the hospital Michael was at, I just really didn't care for it, you know. I really didn't. But Carol, the university, that's where she was hospitalized at. And I did tell one of the doctors, I said, if you all had stopped sending her home, maybe she wouldn't be in this condition.

16:41:31 >> ANN JACKSON: Now, when you said that, you mean had they not sent her home those three times that you mentioned and kept her, perhaps something, she would have had a different outcome.

16:41:32 >> ARMY STEWART: Yeah, that's what I believe.

16:41:57 >> ANN JACKSON: I see. Now, do you have any idea, any ideas like why you think that for both Michael and Carol it required multiple back and forth before they were -- before they received the care that you thought that they needed? Was it because they -- their symptoms just were not as advanced, they were -- they seemed to be doing okay?

16:42:04 Or did you feel as though they needed immediate care the first time you reached out for services?

16:42:13 >> ARMY STEWART: Well, yeah, Michael, I felt that he needed immediate care. But Carol, you know, I thought, you know, that she was going to be fine.

16:42:16 >> ANN JACKSON: Yes.

16:42:29 >> KRISTI KIRSCHNER: Dr. Jackson, I'd like to pause for a moment because I know Dr. Hogarth will have to leave in a couple minutes. I wonder if I could just ask her if there's anything she would like to reflect on or comment on.

16:43:00 >> RANA HOGARTH: Sure. Well, first I would like to thank Miss Stewart for sharing HERstory. And what I would like to simply say just in terms of by way of reflection is it sounds to me in terms of what I mentioned about people being listened to and being taken seriously when you go into a site for care and to recognize that this also seems to be a story of not just there's something wrong acutely, but recognizing well-being

16:43:09 and taking seriously somebody's complaint about something not being right and taking seriously a time to listen.

16:43:37 So that's something that I keep hearing in sort of the recounting of these events of having to go back and forth of sort of the dismissal of these concerns when they're brought forth. And so this is something that I hope in terms of a point of conversation and something that can be sort of acted upon to understand ways to better listen and interface, especially when people are in their most vulnerable state

16:43:46 . The sending someone back and not taking seriously the concern is something that really strikes me in what I'm hearing right now.

16:43:52 >> KRISTI KIRSCHNER: Agreed. It's very poignant and powerful to hear this story.

16:44:03 Thank you, Dr. Hogarth for the time again that you've been able to give us today. And I'll turn it back to Dr. Jackson to proceed.

16:44:06 >> ANN JACKSON: What do you think about what Dr. Hogarth just said?

16:44:22 >> ARMY STEWART: Well, she was on point when she said, you know, taking a person seriously. You're not going to go to the doctor of the hospital unless you feel that something is wrong with you. And you should be listened to, you know, taken seriously, more concern, you know.

16:44:36 >> ANN JACKSON: And I really like what she said about well-being, that it's not just enough to be without disease or to be without illness, but you were also saying that they're not themselves. They're not who they should be. Please help us.

16:44:38 >> ARMY STEWART: Yes, right.

16:44:45 >> ANN JACKSON: And that's what I -- that's what resonates to me. You kept saying please help us, please help us.

16:44:58 >> Well, I want to kind of turn just a little bit and ask you two questions. One, when you are able to get back out and go into the community, what is the first thing that you want to do that might bring you some joy.

16:45:01 ?

16:45:32 >> ARMY STEWART: Just to get out and just, you know, look up into the sky and just reflect on, you know, things being as well as it is in my life, you know. But, you know, I'm not -- you know, I don't go to movies or things like that. And now that I'm by myself, I just really haven't -- well, we can't do anything now. But I never was a person that, you know, went a lot.

16:45:36 But my church is my life, you know.

16:45:41 >> ANN JACKSON: Is your life, a (inaudible) to your life and your well-being, and your well-being.

16:45:42 >> ARMY STEWART: That's right.

16:46:01 >> ANN JACKSON: So I guess I want to just close with this. One is I again just thank you from the bottom of my heart for just sharing your heart with us and your story. And I'm really curious to ask why did you even agree to do this?

16:46:17 >> ARMY STEWART: Because since I met you Miss Jackson, you have just been the sweetest person that I've met in a long time. You show so much concern for me, and I just learned to love you. And I would do anything I could to help you.

16:46:27 >> ANN JACKSON: Well, that is a surprising answer. I was not anticipating that. But I thank you very much, and your check is in the mail. So thank you so much.

16:46:52 So lastly, what should we take away from this? So you shared with us, Dr. Hogarth has commented. What is -- what pearls, what kettle of wisdom as an of such that you are, what pearls of wisdom should we carry after this conversation?

16:47:27 >> ARMY STEWART: Well, when you see something that's wrong, if you see it, speak up about it. And do your best to -- what you can for another person. With love. If there was more love in this world, it would be a better place. But, you know, there is not much love shown in this day and age. But we have to lean and depend on God, you know. Without his strength, you know, I've -- I just couldn't have made it because I feel like God makes no mistakes, so they

16:47:36 left me, and he knew about it, and he didn't choose to heal them. So I accept that.

16:47:44 >> ANN JACKSON: I see. That takes a great deal of inner strength and belief, and thank you for sharing that because I think in these times, we need a little bit more of that too.

16:47:57 So we give you love and we thank you for your strength. And we thank you for the regalness of your display. But we also know what a delicate creature you are and how your loss has impacted you.

16:47:59 >> ARMY STEWART: Yes, it has.

16:48:05 >> ANN JACKSON: So Dr. Kirschner, I would say that really set the tone for our conversation.

16:48:06 >> KRISTI KIRSCHNER: Yes.

16:48:15 >> ANN JACKSON: And I just think so much of Dr. Hogarth's comments and those of Miss Stewart.

16:48:46 >> KRISTI KIRSCHNER: Thank you. Miss Stewart, I also want to echo what Dr. Jackson said. And thank you so deeply. It's hard to actually move on after hearing your stories of loss and trying to take in the weight of everything you've told us. But it's why we need to hear it. We need to think about it, ponder it, and figure out, you know, where can we put love back into our health care system.

16:48:56 How can we try to restore again what health care is really about, you know, make you feel listened to, make you feel cared for.

16:49:09 I do have to ask you one question, though. You've got a fury little friend in the picture at your feet. And I do feel like we need to introduce your furry little friend.

16:49:14 >> ARMY STEWART: His name is Cody.

16:49:18 >> KRISTI KIRSCHNER: It looks like he's a pretty good companion.

16:49:19 >> ARMY STEWART: Yes, he is, he is.

16:49:22 >> ANN JACKSON: He's sleeping by her feet right now.

16:49:40 >> KRISTI KIRSCHNER: Well, I'm glad you have Cody. So Miss Stewart, if it's okay, we're going to turn now to invite our two other panelists who are with us, Pringl Miller and Amy Campbell, to also react and share with us their thoughts.

16:49:56 While we're' doing this, I'd like to begin to invite our audience members to also put questions in the Q and A. You can do so anonymously. You can raise your hand as well. We'd be happy to call on you and have you talk.

16:50:00 After we've gotten some initial reactions.

16:50:25 So let me first introduce Pringl Miller. And she describes herself as a surgeon who works with people who are seriously ill and dying. And that she's a fierce advocate for equity, for minority and otherwise marginalized patients.

16:50:57 And Amy Campbell describes herself as a teacher, a daughter of aging parents, a sister of immunocompromised older sister, and she's also struggling with being a little bit displaced. She was an east coaster who came to Chicago during the COVID pandemic. So she's really been figuring out this new place to live as she calls herself a visitor, feeling like a visitor. Still in the new land. Which she is now making her new home.

16:51:36 So let me open it to Dr. Miller and to Ms. Amy Campbell for their comments. And I'm going to invite them to comment on what troubles them most about the story Miss Army Stewart has shared and what just feels unfair. You know, what in your gut feels unfair. And where were those gaps in services. What perhaps did COVID magnify for us or make more apparent that was embedded in our health care system?

16:51:40 So I wonder, Dr. Miller, if you'd like to start.

16:51:50 >> PRINGL MILLER: Yeah, thank you so much, Dr. Kirschner. And Dr. Jackson, thank you for bringing Miss Army Stewart into our midst.

16:52:11 I just wanted to let Miss Stewart know that you refer to her as a queen, and now I certainly understand why that is. And I just want to also express my condolences for your loss and just how much inspiration you have brought to me in hearing your story and your courage to tell your story.

16:52:22 And your faith and how that has helped you to get through the enormity of what you've gotten THU.

16:52:32 I think, you know, one of the things that has struck me through COVID is the lack of being present in the hospital at the bedside with loved ones.

16:52:46 And how devastating that is for not being able to be there for the people that we love. And you're such a tremendous advocate. I guess I have a couple questions. Are you up for more questions, Miss Stewart?

16:52:48 >> ARMY STEWART: Yes.

16:53:15 >> PRINGL MILLER: Okay. My one question, just because we're really not at the end of the COVID pandemic, and I think there are probably so many more loved ones faced with having to advocate at a distance. If there's anything that you want to share about that sort of advocacy from a distance, because I think that's one of the things that's certainly been hard for people.

16:53:37 >> ARMY STEWART: If they would, you know, just let you into the hospital, you know, to see a your loved ones or to be there to encourage them, because like my daughter told me, she was -- you know, the things they were doing for her and all of that, she was getting afraid, you know. But I tried to encourage her, you know, you're going to be fine, and all of that.

16:53:50 I mean, something they could have done, suited you up or whatever, you know to make your loved one feel better, you know.

16:54:08 >> PRINGL MILLER: Yeah. Did you get the sense from your children -- and it sounds like it wasn't really possible to speak with Michael, if I understood you correctly. But you were able to speak with your daughter Carol and then if I understood you correctly, you were able to also talk with your son Kevin.

16:54:25 Did they communicate apart from their fears and concerns about being in the hospital and perhaps sensing that things weren't going well? That they also were heard or listened to, that their concerns were not being addressed?

16:55:00 >> ARMY STEWART: Well, my daughter, she -- she was very upbeat most of her time in the hospital. It was just the last few days that, you know, she became concerned. And my son, I talked to him that Sunday night. And he said he was sitting up in the chair, you know. He was -- he said I feel fine, you know. But the next day something happened, you know. That's when he passed away that Monday.

16:55:16 So I don't -- I don't know what could have, you know, changed from Sunday night until Monday when he was, you know, getting his dialysis, you know.

16:55:28 >> PRINGL MILLER: Uhm-hmm. Did you feel like the communication that you were getting from the providers at the hospital was consistent or sort of --

16:55:42 >> ARMY STEWART: Well, it was. They talked to me every day, but with a -- my oldest son, they communicated with his wife.

16:56:15 >> PRINGL MILLER: I see. Yeah. So one of the things just to bring into the conversation that's very important to me as an advocate for patients and as Dr. Kirschner said, patients who sometimes are invisible and whose voices are not heard in the way that we feel like they should be or we know that they should be is, you know whether there's enough advocacy, whether there's enough on the ground support for the people that are in the hospital.

16:56:30 And I think that we've been really challenged by that situation just because as we said earlier, you, for example, were not able to come to the hospital and to just see to the fact that things were actually happening appropriately.

16:57:07 And so I think in the way of forecasting how we might be able to supplement in the future, how to make sure patients are heard and properly cared for more pro bus mechanisms of advocacy that connect patients with their family members is something that we could start to think about and perhaps implement. Because sometimes also there's a failure of communication. Sometimes people in the hospital that represent the care teams

16:57:20 can say things that are confusing or might be inconsistent about what they're saying. And so being able to understand also the language can be really challenging. Thank you for being with us today.

16:57:51 >> ARMY STEWART: If they would implement a person that works in the hospital, you could meet with them, say, on the ground level or something and get a real feeling of how your loved one is really really doing, you know, and be truthful. You would feel better, I think, if there was some kind of closeness to your loved one through this person.

16:57:59 >> KRISTI KIRSCHNER: That's a wonderful suggestion. Thank you, Pringl, and let me turn to Amy to see what she would like to.

16:58:24 >> AMY CAMPBELL: Yes, and let me first also echo the thanks before for Dr. Jackson for bringing us Miss Stewart and Miss Stewart for sharing really it's heart breaking stories and to see your strength now. My deepest condolences. It seems unimaginable what you've been through. And so I just think it's so powerful that you're speaking.

16:59:01 And I think law -- I sort of come at it from a law perspective and it seems a bit maybe sterile in this sort of conversation, yet I think sometimes what law misses are these stories, right, that there's people -- you know, sometimes we feel like we're just something on a piece of paper. You read a law, right. But behind it are supposed to be people, people that we're protecting and supporting and helping. And so I think when I think of your story, what troubles me is what's been said alrea

16:59:10 And also this idea of the challenges in communication throughout this process, right, and being able to be near your loved ones.

16:59:34 And it just makes me think when -- from a law perspective when we have laws, do we think enough about who's impacted by our policies, right? And also when we're implementing them, we have good intentions, right? We might want to protect people and keep them safe and keep them separated. But by doing that, are we creating isolation, which is its own harm.

16:59:42 And you wanted to have some closeness to your family members when they were going through this as well as your faith community.

16:59:52 You wanted to have that relationship continue. And we want to make sure that we're not -- when we try to keep people safe that we're not creating additional harms.

17:00:14 We also think about -- I know questions about services that were magnified. I think by listening to stories like yours and hearing such powerful words and thinking about access to care, there were some -- you know, there's preexisting health conditions, right, that COVID really seized upon it and made it more challenging for you.

17:00:30 And so were there things that we can do through our law and through our policies to make sure that we are thinking about access to care that you need, when you need it, where you need it, in ways that are sort of understandable and appropriate for what you need.

17:00:36 And how can law listen to those stories and those voices and really reflect that.

17:01:01 I was so struck up front by Dr. Hogarth where she said medicine and the erasure of Black people's suffering, you know. I really -- I worry that law can hard en that, and we TOENT want to do that. We want to make sure recognizing suffering and preventing suffering to continue.

17:01:04 So I thank you so much for sharing with us.

17:01:17 >> KRISTI KIRSCHNER: I see we're beginning to get some questions, and I believe Miss Thompson has her hand raised. Would you like to unmute and share?

17:01:56 >> Or do we want to start with one of the other questions in the meantime and see if she wants to Connel back -- we can come back to her.

17:02:31 >> I would just interject to Miss Stewart that there are many people who are participants who are thanking you for your contribution to this discussion today. I'm not sure that you can actually see that from the Q and A. But a lot of accolades for you for coming forward to share your story.

17:03:02 Well, the other thing I was struck by was that you -- this -- you know, because I've seen it with my own parents as well, this reliance on computers to get access to vaccinations and how challenging that has been just you know, you have to be on it at the right time and know which site to be on and how to get it and how to sign up and all, and it's -- so it's -- I imagine been very frustrating for you because it's like we know we have this thing that could help, but it is hard to access it.

17:03:22 You hear it's there, but how do you get through? So I'm thankful for your alderman for helping, but I think we have to do better. I think that's been hard to hear there are all these vaccines but we can't get to it, right? Yeah.

17:04:00 >> I would say the other thing that really struck me over the few weeks that Miss Stewart and I have been working on having this conversation is just that each of her children and her granddaughter had underlying health conditions. And I guess I want to draw attention to that because I think that that speaks to the chronic nature of some of the -- some of the inequities that Dr. Hogarth spoke about and how those inequities

17:04:05 are magnified when you come into a situation like this.

17:04:38 And I was definitely struck by the idea that each of them had such medical histories that when COVID struck, there were even more debilitated because of the underlying health conditions. So I just think about just the health of our communities in general and what -- where are the gaps there. So if COVID magnifies them, what was COVID magnifying, and were there ecological stressors.

17:05:01 Where were these inequities that perhaps to Amy's point that we could have -- that we somehow can address with policy or to Pringl's point can we address with more compassionate health care.

17:06:06 >> Yeah, I just -- I just wanted to say that I was very (inaudible) and I really enjoyed your story. And I have a disability myself. I have a disability, and COVID is definitely made things very difficult for me and for -- and for people like myself. So I -- I am, I think -- I think the hospital -- the hospitals need a person that will get -- that will tell people what's going on and what their -- with their loved ones because

17:06:37 people are concerned and they -- and I did the same thing it would be nice to -- because they don't know who they're coming to, so they need to be thankful of the people that they're communicating with.

17:06:53 >> KRISTI KIRSCHNER: Yeah, thank you, Mr. Peter son, for those remarks. I think we can just echo the sentiment that, you know, there's a theme here of communication that is percolating through all of these comments.

17:07:14 In a couple of minutes, I'm also going to have us talk a little bit about how you can share even more about your experiences and your stories during COVID. But it looks like we do have a couple more questions. And I think we have time for perhaps another two.

17:07:44 How about Rhonda white? How do we as health care professionals address a matter of color correction and the need to change diagnostic measurements legally to not reflect these biases? Great question. And anyone want to tackle that? Dr. Miller, do you want to, or would you like me to?

17:07:49 >> PRINGL MILLER: Maybe if you could get started and I'll think about it, I can contribute.

17:08:29 >> KRISTI KIRSCHNER: Well, I think the first thing is to make sure that we're understanding race is a social construct and that should be default. If we don't have actual by logic data, we shouldn't be using these large swaths of self identification, and I think that is changing in medicine. The things that Dr. Hogarth is calling out are a serious concern particularly this correction with creatinine. It makes a difference with health equity.

17:08:34 It makes a tremendous difference in terms of who gets access to being on a transplant list.

17:09:08 So I think we're finally beginning to say does it make any sense what's the data to really make that a valid construct and unpack how did it come to be. And you'll find out as you start to unpack these things, that oftentimes they're on very shaky grounds.

17:09:10 I don't know if anyone has any thoughts about that.

17:09:51 >> PRINGL MILLER: No, I think what you said was right and going back to what Dr. Hogarth said about myths and the generation of myths over the continuum of time for hundreds of years, perceptions that are projected on to different peoples by other peoples without study or in depth evaluation, and one of the things that is sort of two things tied in together has to do with just the lack of data that we have on certain conditions as it relates to African Americans or BIPOC folks.

17:10:01 Which what we're finding is that we're extrapolating certain ideas on to people who haven't actually been the people who have been studied.

17:10:41 And one of the things I was going to say earlier about the vaccination, we're going on to a different topic, is the other myth was true although we do have some Pugh study data about the number of Black people in society who don't want to be vaccinated. But I think there's a tendency again to make it seem like the bulk of Black people don't want to get vaccinated when that's not really true because I was very encouraged to hear that Miss Stewart was really working on getting vaccinated. An.

17:10:46 But I'm going to pass the baton to Amy Campbell.

17:11:22 >> AMY CAMPBELL: Gosh, and I'm a lawyer. We don't like to not speak for a long time, right? But I will do my best. I'll just mention briefly that for the legal intervention, certainly we do have laws that exist now. We have civil rights laws that should be, you know -- we need to hear these stories, right, that we'll hear them as we know we have laws behind it that we can use to address discrimination based on any number of factors, including sort of race, national origin, you know, sex,

17:11:43 We also in this instance have public health laws that will address when there are sort of the population's health, right? How can we move towards the good of communities and individuals within those communities and perhaps allow us to maybe infringe on some individual liberties to do that.

17:11:46 And that can be a powerful tool.

17:12:07 And I also notice there was another question sort of about I know law is sort of slow. It takes awhile. And my two thoughts in that is certainly we could see within law, like law also is an appropriating tool so are there resources that law could maybe allocate towards organizations who are on the ground making sure that they can help people.

17:12:37 And the other thing I'd offer is that I hope that we can start to think of policy itself as an intervention. And so are there ways that when we're passing policies, we're collecting data, we're listening to the stories and making sure we have it right so we can change it more quickly and in real time, for instance, the vaccination and realizing we can't do it quicker on the computer. So hopefully law does take some time and we want to empower

17:12:45 change on the ground but also let's look at ways we can have a more rapid response, let's say, with our policy interventions.

17:13:12 >> KRISTI KIRSCHNER: So we have one more question from the audience about the lack of care that was demonstrated by the emergency medical system with Miss Stewart's child that you called three times and you were given pushback about taking Michael to the hospital.

17:13:37 The questioner is asking, you know, what was behind that? And can those things be reviewed? Can they be subject to oversight and review? How do we make sure that there's some sort of quality and safety assessment of those sorts of decisions. Where are my implicit bias or explicit bias be in that kind of decision making?

17:13:50 So how can we begin to bring these things to light and change them? It's a complicated and wonderful question.

17:14:11 >> PRINGL MILLER: Well, certainly some of the ways is to have more training around being able to identify when there might be implicit or explicit bias when you're treating someone. And that type of understanding, I think, is being more incorporated into the processes that happen within the clinical space.

17:14:24 I think we also as people of color understand that the more people of color that are working in these spaces will impact the way in which people are cared for in these spaces.

17:14:39 There's definitely good evidence to suggest that women and underrepresented minorities can enhance the care of women and underrepresented minorities that are getting care.

17:14:52 But I think that we can't continue to have blinders on about the disparities that we see between the care, the access, and the outcomes that different people are experiencing across our society.

17:15:00 >> KRISTI KIRSCHNER: So I'm going to throw a little wrench into this discussion because I think that there are also issues between hospitals.

17:15:34 So by the time he got there, he was in the emergency room for seven days. That hospital was swamped. They didn't have beds. So what happened to try to make sure that patients could get the care they needed by communicating with other hospitals? Was there an infrastructure? Were there support services? Because that may also have been behind a little bit of the push back, you know, from EMS when you call 911, you go to your closest emergency room. That's the way the system works.

17:15:51 But then how did we have mechanisms to make sure that if that emergency room that you're closest to or that hospital didn't have the capacity to provide care, that they were getting transferred to hospitals that would have capacity.

17:15:53 I would just ask that question.

17:16:01 And I think that's a quality question for the system. How was the system working?

17:16:21 >> ANN JACKSON: Miss Stewart and I were just thinking about had the EMT teams when they came, even if they had given her a card with their names on it, because what happens when they're dispatched, they can come from any -- they come from a firehouse in the city. They come from a firehouse that's close to you.

17:16:46 But if it's -- so if it's an EMT versus an ambulance service, and even if she had just had a card with their information on it, then perhaps there would have been opportunity to hold to at the very -- at the most micro level, there would have been an opportunity to be able to call someone back and say, I called you three times about my son. This is what happened to him.

17:17:15 And I think that even that, because I don't know that that ever happens when an EMT comes to your home, if they ever leave any identifying information with you that you can read. Oftentimes they sign off on the paperwork, but often you can't read the signature. So it would be nice if, you know, (inaudible) who came to the house.

17:17:38 >> KRISTI KIRSCHNER: So I think we're beginning to generate some potential ideas or things that we want to capture. And I want to acknowledge the suggestion from Don piper saying, you know, there's a need to involve health professionals across the spectrum that dentistry could help close some of the gaps in access to care.

17:18:09 So I think what we need to move to actually is a little bit more orientation to the series and how you can begin to share your ideas, your stories with us. So I'm just going to move quickly here, and I'm going to ask -- this is a rhetorical question. I was very struck by the work Dr. Sanjay Gupta, the CNN chief medical correspondent is doing.

17:18:18 And one of the things he's doing is he asked every doctor that he's interviewed and he's done over 20 hours worth, what do you think the final cause of death was?

17:18:47 So if you look at death certificates, you may have, you know, immediate cause of death was COVID, but then you've got the antecedents. And so if we were to consider what were the antecedents to the deaths of Miss Stewart's children or other people who have been lost with COVID, what would we say? That's a question that we can ponder as we move through our series.

17:19:03 I also am just going to highlight that as we talk about stories, stories are absolutely central because it tells us something about the moral life of individuals, what matters to them.

17:19:35 I want to just call out on the website we have a Ted talk FRL Sayantani Dasgupta about the narrative humility. We hear stories, but we can never fully understand another person's lived experience, as much as we're all moved and struck by Miss Stewart's telling of HERstory, it's her story. So we can listen, we can try to understand it, put it into context of this larger and social political narratives.

17:20:13 But the story is her story. And part of what we bring to stories is what we call close reading skills or close listening skills. And that's really important to actually attend to the exact words and not project our ideas about where we think our stories -- the story's going or any stereotypes or trope that can be embedded no a story. Real listening is learning and that's what we're trying to do with this series. We're trying to use these stories to figure out where do we go. How do we tran

17:20:33 health care and these are complicated problems. But at the end of the day, we're trying to figure out how we can change those preexisting health inequities that result in health disparities in an adequate access, unequal access, and then how do we also move forward, particularly before we're faced with the next pandemic.

17:20:38 What would we want to embed in our health care system?

17:20:41 So we're looking for action oriented steps.

17:21:06 So I'm going to pause at this moment and introduce Gaby Pena who's been part of our steering committee and our team working on the series. Gaby's going to tell us a little bit about how the jam board works. She identifies as a daughter, a sister, an aunt, a survivor of invisible chronic illnesses and a champion of social justice and public health.

17:21:10 Gaby, I'll turn it over to you.

17:21:16 >> GABY PENA: Thank you so much, Kristi for that gracious introduction.

17:21:30 So as we have noted previously, something that we have been very intentional about is wanting to make sure that we can go ahead and facilitate practical and actionable solutions to these systematic issues. A.

17:21:48 And so I welcome you all to please use jam board. I'm going to go ahead and -- may I please have access to sharing my screen, please? Thank you so much.

17:22:26 So provided on our series website, I invite you all to scroll down and you will see the -- join the discussion box. If you select this brief presentation on jam board basics, it will send you over to a brief jam board 101. And so I just want to note that one of the -- the benefits of us using jam board, because we do want to make sure that everyone has the accessibility to use jam board, is that it can be used on

17:22:35 any type of operating system. So Macs, PC, mobile devices. So that includes both cell phones and tablets.

17:22:54 However, please do note that as I will show you ORN the next -- on jam board itself, that the editing tools might not be on the left-hand side of your screen as it would on a computer or a tablet. So just something for you to keep in mind.

17:23:06 Additionally, it does allow for real time editing. So multiple people can go ahead and edit, add comments. And it also auto saves.

17:23:24 So please don't worry if you accidentally X out of your window. Whatever you edited or add the will be saved. So I know a lot of us have so many windows open. So please don't fret about that.

17:23:53 So as I mentioned, you will see a tool bar located on the left-hand side. And so some of the tools that are allowed on jam board are a pen, an eraser, a sticky note, which for the purposes of our seminar series, I highly recommend you all use. Additionally, an image, a circle, text box and a laser. But again we will really only be focusing on using the sticky note.

17:24:13 So in the next window, I will open up jam board. And I will walk you through where the sticky note is, how to change the color, the text. Feel free to also move it around in case, you know, space is a little bit of an issue.

17:24:20 You are able to resize and also change the angle of the sticky note as well.

17:24:45 Additionally, I know that not all of us are going to remember all of these -- all of the notes that I have just mentioned, so again please feel free to go onto the website, hit the join the discussion, and then please click on this PowerPoint and you can go ahead and go through these slides at your leisure.

17:24:55 Also I know that, I know, questions might arise from now through the rest of the seminar series.

17:25:09 So I do want to make note that there is an additional questions frame. And so you'll notice that on jam board itself, there's different frames for each of the four seminar series.

17:25:33 However, if you have some general questions about the format of the series, or just about the seminar series as a whole, I do welcome you to add your questions via sticky note on that additional questions frame, which I will show you momentarily. And I do ask that you use a sticky note color that's not green.

17:25:44 So the members of the steering committee and our panelists will be able to access, and we will really try to answer questions using a green sticky note.

17:26:20 So without further ado, I'm going to go ahead and transition over to jam board itself so as you will note, there are one of eight different frames. So for the purposes of this seminar series, the title -- the frame corresponds with the name of each seminar series. So for today's event, please add any questions, comments, reactions to this slide titled setting the stage for transformational conversations.

17:26:37 Here is the sticky note tool. So if you click on that, you'll see that the sticky note pops up as a reminder. You can go ahead and select different colors of the sticky note and you can add your text.

17:27:01 You can go ahead and then hit save, and then you can go ahead and press down, drag it around. This circle on the upper left-hand corner allows you to change the angle of the sticky note, and then any of the other circles will allow you to resize.

17:27:34 And as I did mention earlier, we do realize that not everyone had the opportunity to ask a question. So slide 5 of 8 is our additional questions. So again, if you have a question, go ahead and add a sticky note and please select any color except for green as the members of the steering committee and the panel will try to answer your questions using the green sticky note.

17:28:11 Also if you have any other questions about jam board, this is also provided on the PowerPoint slide. Please feel free to contact me at GPena5@UIC.edu. I will also add my (inaudible) to the chat. And that is it for jam board. I am very excited to see different questions, comments and reactions, and I hope that you all have the opportunity to use jam board. Thank you.

17:28:43 >> KRISTI KIRSCHNER: Great, Gaby. I wonder if you could give me that shared screen so I can show one more slide. Let's see here. It's not coming up, is it? Can you see it?

17:28:44 >> Yes.

17:29:15 >> KRISTI KIRSCHNER: Okay. So we wanted to tell you about another way you can be engaged, and if you want to write your story about what you've done when you've identified a gap or an inequity during COVID, and share it with us at this link, we are going to select five stories that we're going to include as case studies in our report. And we will be able to offer a stipend if you're one of the stories that will be chosen.

17:29:26 We're looking for stories that illuminate about gaps and services, collaboration, look for investable disparities.

17:29:42 We want statements of unmet needs. We want to have a description of the nature of the response, the outcomes, as well as the barriers, the facilitators and the barriers. But we're trying to focus on what can we do to work better together.

17:29:49 So please, think about whether you'd like to be a partner with us as we move forward in the project.

17:29:56 And finally next Wednesday we have our second panel, which will being exploring intersectionality and social vulnerability.

17:30:01 So we hope you will return and join us for that.