okay so for those of you who saw my original Talk title don't be disappointed um we will be covering

0:11

those topics um but as I got to putting together the slides and really thinking about what I wanted to say to you today

0:18

I thought this was a more fitting title what about Justice um so before I delve

0:24

into kind of some of the content that I want to talk about today I'd like to give you a little bit background of how

0:31

I got interested in this topic and how I came to be someone who studies Justice and health and

0:39

Equity maybe I want to do that I can get my slides to move

0:47

forward let's try that [Music]

1:04

all right now my slides are moving forward now um so I uh have a screenshot

1:11

here um of a very young picture of me um from

1:16

2010 um that top picture is me and my happy bright and unjaded face as a fresh

1:23

graduate getting my match letter to man's greatest hospital um and that

1:29

picture below um is a picture of my head shot again bright naive happy excited ready to go

1:36

into the world um and so as a medical student at Case Western Cleveland Clinic

1:42

learner College of Medicine um my third year I was pretty sure that I wanted to do GI and hepatology and so I was doing

1:49

a rotation and one of the residents said you know one of your patients is going

1:54

to be presented today in liver transplant committee meeting why don't you go to the committee meeting and I

2:00

said okay I said I think he's just trying to get rid of me but it may be interesting okay so I went I sat in the

2:06

back and I came in with this kind of idea of what I expected to happen I

2:11

expected like a big screen to come down and for like all the names to go up on the board and for everybody's clinical

2:18

information to come up and there to be this rigorous discussion about how we can get people to

2:24

transplant and that wasn't what it was um my expectations did did not get met

2:31

um and I can say since that time I have been to many transplant committee me at different centers and there was nothing

2:38

wrong with the transplant committee meeting to happen at Case Western but it was not what I expected it was people

2:44

eating lunch people answering Pages people saying why people weren't eligible without thinking about

2:50

Solutions it was what to me seemed like very casual uh for something so

2:56

substantial um and my patient was not listed he was thought that he did not have enough social support and it was

3:02

given very short discussion um and I was shocked I left that committee meeting

3:07

and I remember uh telling my senior I can't believe this is how committee meetings go was this some type of

3:13

anomaly nobody seemed to be trying to help this patient and he just looked at me and and shook his head um and then I

3:20

had that same conversation with family and friends afterwards and everybody nobody was quite sure why I was so

3:25

bothered but I was very bothered by the whole thing and so I said well I wanna I

3:30

want to be able to talk about this and use some terms and talk about these things that I'm feeling and experiencing

3:35

and this fairness that I feel like is not there in some kind of educated way and so I started Googling um liver

3:43

transplant and fairness and I I came ac across some things about art kathan and

3:48

other folks and I said um maybe if I take a bioethics class I'll be able to

3:53

kind of Express what I'm feeling and talk about it um in a more meaningful way so I took a bio ethics class and a

4:00

bioethics class turned into a bioethics masters um and that's how I landed in

4:06

this space um really wanting to be able to express what I was seeing the

4:12

problems I was seeing in some type of way that wasn't just emotional it wasn't just this doesn't seem like it's right

4:18

um and that's how I became kind of or got on this path of exploring um Justice

4:24

and social justice from a bioethics framework so I learned learned a lot of

4:30

different ethical constructs in transplantation um as a bioethics

4:35

student um that did arm me with some tools to write a lot of good editorials and so we'll we'll run through some

4:42

ethical constructs um in uh transplant I learned about scarce resource allocation

4:48

right and and this idea that there's not enough um to go around and you've got to

4:53

think about how to distribute them fairly um and effectively um and I actually wrote my kind of Master thesis

5:00

around this concept of scarce resource allocation and kidney uh

5:06

transplantation I learned about distributive justice um this concept that even in the setting of scarce

5:12

resource allocation um you have to still understand how the burdens and the

5:18

benefits in healthcare are allocated and distributed amongst all individuals and

5:23

so that seemed to get at a bit of what I was feeling in that committee meeting that yes there's a scarce resource but

5:29

can we ensure um that some people aren't bearing all of the

5:35

burdens autonomy um of course was something that I learned about um that

5:40

you know people have to make informed decisions about whether or not they want to partake in healthcare even transplant

5:46

it's a life-saving Endeavor but everybody doesn't want to do that and that's okay um and there's going to be some people who need to be able to

5:53

express that kind of autonomy um that they aren't interested in transplant for whatever their reasons may be

6:00

he learned about how to be a benefit right um to patients and really thinking

6:06

about transplant and the people who are going to have the best survival and so that becomes a big topic and a big Focus

6:13

that we'll talk about more in transplant and of course we want to do no harm um we want to pick the people

6:22

who are going to have the best outcomes and then finally um some of the concepts

6:27

that I thought about were moral distress um and so I think sitting in that meeting I felt a bit distressed um some

6:34

discomfort um as a clinician um and feeling like there was some injustice and that there was nothing that I could

6:40

do about it and so I was armed with this framework um and and I've written um

6:45

editorials and I've I've thought about these Concepts and and how they applied to the patient that I saw in medical

6:50

school and many of the patients that I see today but I still have to say that even over a decade later I'm left with

6:59

this question it doesn't burn me in the same way it did as a medical student um but I still feel like of the four major

7:07

ethical principles um in transplant and in health care autonomy beneficence

7:14

Nance and Justice why does Justice see receive the least

7:20

attention why is Justice the stepchild of all of the ethical principles and

7:27

what can we do about that and what would it look like what would

7:33

Healthcare look like what would transplant look like what would the world look like if Justice were treated

7:40

as a equal ethical principle in transplantation and so armed with kind

7:46

of the framework about how to think about these things this is the question that drives me every day this is why I

7:52

get up every morning this is why I do the work that I do this is why I apply for grants in the face of executive

7:58

orders because I want to know what would the world look like if people cared as

8:04

much about justice as they did about autonomy so these are objectives that we

8:11

will cover today we will um examine those four ethical principles and we

8:18

will talk about how they're coded into health care and Transplant um and we'll

8:23

talk about how Justice really is not we will then review some of the disp

8:29

ities in liver transplantation and highlight some key access and outcome issues that I think happen as a result

8:36

of really our lack of focus on Justice and then we'll talk about the

8:42

consequences of a failure to deal with our justice issue and because I think

8:48

that there's this idea that not dealing with Justice and not dealing with health and Equity is somebody else's problem um

8:55

but Injustice has consequences okay um and so we're going to talk about public

9:01

perception in Justice and the consequences in organ donation of our lack of focus about uh justice and

9:09

trust and then we're going to dream and talk about what if we were to

9:15

reimagine a just transplant system if I could have some of the things that I

9:21

would like that I would think would move us away from where we are now what they look like um and so we'll end on a on a

9:27

high note but let's start with talking about some of the uh ethical principles in

9:34

healthcare and Transplant and how they are coded um in a part of our kind of

9:40

framework in a way that I think Justice is not so autonomy is a patient's right to

9:47

make their own medical decisions we all understand it and it is legally

9:52

protected okay um the principle is reinforced through informed consent

9:58

shared decision making um if I leave a endoscopy room and I have forgotten I've

10:06

talked to the patient about the procedure I've explained it but for some reason I didn't get their signature and

10:11

I didn't sign the consent form there's five nurses chasing me down the hallway to make sure that those consent forms

10:18

get signed before I put that scope in the patient okay um and so we have

10:24

processes in place to make sure that patients autonomous is documented um

10:31

there are many of us in ethics who spend our career reading about writing about

10:37

talking about informed consent um if you want to overcome someone's autonomy what

10:43

are the situations where that's possible right um so there is um this is not

10:49

something that's just ethical though right this is legally mandated um and there are many processes in place across

10:55

all of healthcare to ensure that people's um autonomy is not violated um

11:01

and so if you would violate someone's autonomy and you know the accreditation folks come and see that there's consent

11:08

forms that are dated and timed after I did the procedure we get dinged our

11:13

endoscopy Suite gets dinged and if you have too many of those that you don't correct you can lose your privileges and

11:19

if it lands on one physician that they aren't getting you know adequate informed consent you know that could be

11:26

a lawsuit right so these are things that are uh ethical principles that we talk about and we write about and we

11:32

pontificate about but they're also regulated um in our laws in our practices at all layers of healthcare to

11:40

make sure that they're respected and I have to say uh you'll see where I'm going with this Justice

11:46

really not so much right um

11:52

nances uh Do no harm um it is also um a

11:57

core ethical principle right um a core principle in medicine that we learn about in medical school um that we

12:03

should do no harm um and we don't want to hurt patients um but it's not just something that we take in our Oaths and

12:10

that we talk about when we get you know um we walk across the stage um to

12:15

receive our kind of you know cap and gown um there are many safety checks to

12:20

make sure that we do no harm to patients right um and so there's infection control protocols if you're on impatient

12:27

service everybody wants to make sure you a gown did you walk out of the room without washing your hands there are

12:32

people who police to make sure that you are not going to pass C death from Patient to Patient to Patient um this is

12:39

something that um is happening in every hospital across the country um there are medication Safety Systems so that we

12:46

scan medicines and make sure that patients are getting the right doses at the right time there's surgical

12:51

checklist their time outs before I can put an endoscopy scope into a patient we have to do a timeout and confirm that

12:58

this is the right patient getting the right procedure and there are many people to make sure that I don't skip

13:04

past that and how many surgeons and proceduralist like me would skip past

13:09

that if there weren't checks in place right it's like ah I know this is the right patient right but it never happens I have never scoped the patient without

13:15

a timeout because there are processes in place to make sure the doct nephew gets

13:21

this done okay um and so a failure to uphold these things if you've got SE if

13:27

running rampant through your hospital if you've got you know infections you will not be

13:33

reimbursed your hospital just will not be reimbursed um and within transplant

13:39

similarly um you know the Mel score was a system is designed in some ways to

13:44

minimize harm right the meld score for those of you who don't do transplant is a allocation score um it's a score that

13:51

tells us how sick the liver is it helps us decide to decide who moves to the top um of a transplant list um and so

13:58

allocation is design to um to take the sickest people first um and it's upheld

14:04

through laws and policies um to make sure that we're abiding by the Mel score and the Mel score is what we're using to

14:09

alligate uh organs um and so um all of these protocols that are in place um

14:16

safety protocols around medicine around transplant around surgical Protocols are

14:22

all put in place so that we don't harm patients um and it's not just left to I

14:28

hope that Dr nephew doesn't harm patients um this is uh there's lots of

14:36

systems to make sure that I don't do

14:42

that you also have an obligation to not just not harm patients right we have a a

14:48

obligation people don't pay us for us just not to harm them they want us to be a benefit to them right um and so

14:54

benefices says that Healthcare Providers are are supposed to benefit p Pati and really act in their best interest and we

15:01

we take the hypocritic oath and that's a really big part um of why we do what we do but again it's not just an oath okay

15:09

they are evidence-based um protocols that guide everything we do um they guide how we

15:15

treat cancer how we treat infection how we treat preclampsia um and if it's

15:21

discovered that you're not following evident evidence-based protocols you can lose your license right um because not

15:27

only are you not supposed to hurt people you're supposed to be providing care that's in their best interest you're

15:32

supposed to be benefiting them following practice guidelines of the current best data and so we meet in groups to make

15:39

sure that we all are following the same practices that you know everybody in our group is doing pretty much the same

15:46

thing um and so these are important um parts of benefiting patients in

15:51

transplant we do the same thing we have listing criteria um that explicitly kind

15:56

of help us to identify the patients we're going to benefit the most from transplant so these are things again um

16:03

that are regulated codified in medical care to ensure we do the right

16:09

thing what about Justice well I would say there's

16:15

lawlessness Anarchy um it's all over the place right

16:20

um there's uh not a similar understanding uh or codification in

16:27

medicine that this principle is anywhere near as important as autonomy um now

16:33

malus and uh beneficence and so what kind of

16:39

structural implementation do we have of Justice in US Healthcare and Transplant system there's been some some Oaths that

16:46

talk about Justice okay so the Declaration of Geneva um the original

16:51

one in 1948 and the revised one in 2017 is probably the closest kind of code in

16:57

medicine that we has that really gets that Justice um that it says I will not permit considerations of age disease

17:04

disability Creed ethnic origin gender nationality political affiliation race

17:10

sex or social standing or any other factor to intervene between my duty and my patient and so I think that's pretty

17:17

explicit kind of a justice statement the modern hypocracy

17:25

will remember that I remain a member of society with a special obligation to

17:31

allow all my fellow human uh to all my fellow human beings those of sound mind

17:37

and body as well as the infirm maybe that's a justice statement it's not quite as clear um as the Declaration of

17:44

Geneva but maybe that's a Justice um statement um but beyond that um unlike

17:50

the other ethical principles this is rather debated and not embedded it's

17:56

talked about it's discussed it's argu argued it's executive ordered but it is

18:01

not um embedded in our practice um and there really no systemic safeguards to

18:07

really ensure or guarantee that anybody gets Equitable care or Equitable access to

18:12

transplantation and so Justice is this kind of idea if you've ever seen this Giving Tree right that um everybody has

18:20

access to the same apples everybody's got the same tools um and then there's this perfect system where everything is

18:27

equal um but unfortunately that's not the world we live in we live in a world

18:32

um of inequality um where there's unequal access to opportunity um and some people have privilege and some

18:38

people don't and people don't have ladders and everybody's trying to get to the same place um but there's really no

18:43

safeguards to ensure that that can that can happen um and so I hope I've I've

18:50

got you thinking even if I haven't convinced you um that the ethical principles that we all study they mean

18:57

something in healthcare they they're codified they are part of why we do what we do um and they are abided by and irbs

19:06

and everybody make sure that we do a good job um but not so much with Justice um and I think that that's unfortunate

19:11

and I think that's why we are where we are today so we're going to talk a little bit about where we are today um

19:18

with disparities and liver transplantation um because I think this is a result of the lack of um focus um

19:27

code requirement um um in this space and so we're just

19:32

kind of out here willy-nilly and that really doesn't get us anywhere um so therosis um is a pretty

19:40

prevalent condition um it was 0.6 per 100,000 in the 90s now we're at

19:48

132.5 per 100,000 in 2017 and you can just see that this barograph is steadily

19:54

inching up and so while therosis may not be a problem that comes to your mind

19:59

like heart disease or breast cancer but it is on the Rise um in the setting of

20:05

alcohol Ade epidemic and obesity epidemic we expect um that mortality from therosis will continue to rise over

20:12

the next decade and so this has becoming a real serious public health issue it's

20:17

always been a public health issue but it's becoming more to the attention of folks who may have been focused on other comities than

20:25

before this is a a complicated figure if you're not of hepatologist but there's really just one thing I want to point

20:31

out um and that is that if you have decompensated liver disease liver

20:36

disease with complications your fiveyear survival is 85% um or your fiveyear mortality excuse

20:43

me is 85% um so this not only is a condition that is on the rise it is a quite more bit condition um and so um

20:51

and unlike other chronic diseases like kidney transplant where you can go on

20:56

dialysis and live live a fairly decent life perhaps or heart failure where you

21:02

may even be able to get a elad and that can help pump your heart for for several years um in liver transplantation

21:10

there's really no other solution you either get transplanted or you die um there's really no Bridge or temporizing

21:17

measure um and so I think when we think about equity in solid organ transplantation in liver disease is

21:23

particularly important because of that lack of bridging therapy

21:29

we're doing more liver transplants than we've ever done before um here at IU we did I think 212 or so liver transplants

21:36

this year when I started here um eight years ago I think we were doing 120 so

21:41

we are doing more and more liver transplants not just at IU but around the country because of some of the

21:46

advances in technology but as you can see in this figure um that despite the fact that

21:52

we're doing more liver transplants which is in the red look how high the weight list is right so just all these people

21:59

um who are on the weight list um who will not get transplanted and this is just the people on the weight list right

22:05

so we're not even talking about the people who never make it to the weight list because of um barriers and access to care um so the burden of people who

22:12

are dying without transplant is probably a lot higher than what um this figure um can um

22:19

display disparities and access to transplant happen um not just at the weight listing space um they happen

22:26

along the whole care Cascade this this is a figure that I like from n the national um Academy of Science

22:33

engineering and Medicine um this is a report they did on transplantation um and it just takes you through some of

22:39

the steps that people don't think about um as much when they think about solid organ transplantation because a lot of

22:45

the disparities start all the way at the diagnosis and disease management step some people might not have needed a

22:50

transplant if their hepsy had been diagnosed right um and treat it because we can cure heepsy now um so awareness

22:56

and education and all the things that lead up to referral evaluation and then

23:01

weight listing doesn't come till here and so much of the focus around Justice and equity and transplantation um if

23:08

there has been any has been at this step right but there are all of these steps that happen before and as we think about

23:13

preventative care and um chronic disease and organ transplantation there's so many things Upstream that we could do um

23:20

in my mind um to kind of help this process I'm going to share with you a

23:27

few um parities for uh some groups so that you can kind of get a context of or

23:32

idea about where we are um starting off with women um and this figure just describes kind of the steps in the care

23:39

Cascade from pre-evaluation evaluation weight listing and a post liver transplant outcomes um and you can see

23:47

that that print came out a little smaller than I expected but um women um are less likely um to um to move from

23:56

diagnosis to evaluation from liver transplant um a study at the University in Michigan showed that women um were

24:04

less likely to be listed even when they in evaluation often due to active substance use issues than men um at the

24:10

weight listing step women have a 50 to 30% higher weight listing mortality than

24:15

men um and are 20 to 30% less likely to undergo liver transplantation and then

24:21

post- liver transplant women have lower quality of life scores um difficulty with psychological adjustment um

24:27

distress um personal um function and so there disparities for women at every step in a

24:34

care Cascade that could be explored when you think about um how

24:39

long we known about disparities and liver disease um or gender disparities and liver disease the sex inity was

24:46

first described by simply moand at Duke in 2008 and if you were to take how long

24:51

we known about it before we did anything about it I think it's been maybe a year since we made a modification to the meld

24:58

score to correct for um to give women a little bit of extra boost okay that just

25:04

happened but we identified this SP in 2008 uh oh uh

25:10

oh um assuming that we had done something about this many years ago 800 women probably would have um still been

25:18

alive and so doing nothing about these disparities and kind of just sitting on them and hoping that they're going to

25:23

get better on their own without changing metal scores Without Really changing policies um is really um life-altering

25:31

and deadly um for the populations who are at a disadvantage Beyond gender I'll show you

25:37

a little race and sces data right here from IU um we looked at over 3,500

25:43

patients who were referred to IU for liver transplantation evaluation between 2011 and

25:48

2018 um you can see the demographics of the people who are referred um 41%

25:55

Medicaid uh 12.5% rural 39% women so our

26:00

referral um patient population in many ways does mirror the population of

26:06

Indiana except for by race all right so 12% of hooers are black and only 6% of

26:12

those who are referred um were black and understanding that um there's a higher

26:17

burden of liver disease in many racial and ethnic bity groups we probably would expect to see over 12% just like in

26:23

Medicaid 40% of hoers don't have Medicaid I think it's somewhere in a 20 to 30 per range but that population has

26:29

more uh liver disease so as expected you see that they're over represented and so you would expect to see that uh probably

26:36

in Rural and in Black patients when we looked at who was dying

26:41

during eval um for transplantation uh we didn't see race or gender differences

26:47

but we did see that coming from a a neighborhood that experiences poverty um made you 50% more likely um to die

26:54

during transplant evaluation this was when controlling for race gender um individual social economic status

27:00

disease comorbidity liver disease severity and this still stood the test of a robust um

27:07

evaluation um and then on the weight list we saw the weight listing um the neighborhood poverty was also associated

27:13

with weight listing and so when people thinking about what are the solutions how do you

27:19

fix um some of these disparities that I'm talking about one of the thing that comes to your mind is

27:27

um that National policies Medicaid expansion um I think we have a tendency

27:33

to really want to push the buck on Justice to somebody else okay um and so

27:39

um that's how I thought when I first started doing this work I said I want to look at and see you know how to Medicaid

27:45

expansion help these problems because that's the way to fix um Health disparities um and so what we found um

27:52

when we looked at the impact of Medicaid expansion on access to the weight list for transplantation um we can see that

27:59

in the kind of grayish blue bars um that there was some small increase in Hispanic patients um listing um but

28:06

there was not the similar increase in white or black patients and so um while

28:12

policy is important it is necessary um National policies around Insurance are

28:17

not sufficient to deal with the justice issues that we have in

28:23

transplantation some people would say well our Health Care system is just not as as robust well I can tell you they

28:30

have the same problem in Canada okay so this is Canadian data looking at area level income um and as association with

28:38

liver transplant access um this is a populationbased cohort over a 20year period of individuals from Ontario

28:45

Canada um and what they found was that living in a poor neighborhood once again was associated with um um a 50% less

28:54

likelihood almost of being transplanted and this is in a place where they have Universal healthare and so again I'm not

29:01

knocking Universal healthare I don't want to or Medicaid expansion I think that these are very important programs

29:07

and that they are necessary for us to do the additional work we need to do to codify justice but they aren't

29:13

sufficient and so this idea that if they just do more in Washington this problem would go away is likely not true um

29:20

there's more that's going to have to be done than just giving people Universal healthare um to deal with the inequities

29:26

that we have here um and trans in healthare in

29:31

general so what does the public think about our Justice problem maybe it's just me right maybe I'm the only person

29:39

who has a problem with Justice maybe it's just me the seed was planted as a medical student and nobody else is

29:45

bothered by this that's not true okay um so the public doesn't trust us either

29:52

okay uh so this is data from the 2019 National survey of organ donation attitudes and practice practices it's

29:58

over 10,000 participants in this survey um they over sample and make sure that they've got demographic representation

30:06

of Asian Americans Native Americans black Americans it's a very well done study um and so if you look um at the

30:14

number of folks who believe our donation system is fair it's about

30:20

66% maybe we think that's a win but if my you know I don't know that's like my

30:25

my son coming home and telling me I got a 66 % it's like 40% of people don't

30:31

think our distribution or donation system is fair I would say we have some work to do there um if you ask people do

30:38

you have an equal chance of getting an organ if you're rich or poor about 52% of people believe that to be true so 50%

30:45

of people don't believe you have an equal chance of getting an organ if you're poor okay and then more striking

30:51

and maybe hard to read um is that uh 48% of people now believe that minorities

30:57

are less likely to receive an organ transplantation and you can see the increase they do this study every five

31:03

years or so so you can see that went from 29 to 30 to 48% we aren't just

31:09

asking minorities this question they ask everybody this question everybody knows the system isn't right right so people

31:15

recognize and perceive the Injustice we're not like hiding back here in healthcare um they recognize that the

31:22

system isn't quite right why is trust important in Oregan

31:29

allocation this is arap quote I don't believe everything he says but I think this is a good one um the values of

31:35

altruism and autonomy the foundations of organ procurement rest on the presumption that organs which are given

31:41

freely voluntarily and altruistically will distributed in a fair and impartial

31:46

manner to those in need any policies practices or activities that suggest otherwise and Peril the entire

31:53

Enterprise of voluntary and alteristic organ donation and when the public

31:59

declines uh trust declin so does Oregon donation rates and that's been shown in

32:05

several studies and so the Public's perception around organ

32:12

transplantation and their and perception of inequity and lack of fairness it just

32:18

keeps that organ donation number low you see how many people are on the weight list right if we want people to really

32:23

buy into the system then we've got to get over people's um perceived um I

32:29

don't even want to call it perceived their recognition of the injustices in the

32:35

system and so this is something that I in my mind I just describe as kind of a

32:41

vicious cycle um this Justice trust cycle right um so when Justice is embedded into policies and practices it

32:48

builds trust people trust the system they perceive it to be fair they think

32:54

transplant is Equitable and all is well so when Justice strengthens trust trust

33:01

increases participation and organ donation and then precip uh participation reinforces Justice because

33:08

if everybody's involved in the system everybody's making recommendations about how to move things forward you got community engagement and you just go

33:15

around this nice pretty kind of Justice trust um cycle if things are going right

33:21

when things are not going right the cycle gets broken right um so breaking a cycle through unequitable policies and

33:28

uh practices leads to distrust disengagement people aren't a part of

33:33

the process they don't want to donate they aren't a part of making rules about the uh the system because they don't

33:38

feel like they're they're even consider um and then you get whing disparities um so I don't think we're in the left box

33:46

unfortunately when it comes to transplant I think that this cycle um is becoming broken and it's evidence as 49%

33:54

of Americans recognizing that that really there's some infer unfairness is happening we looked at this um question

34:03

of whether or not um people's perceived inequality when infect uh their

34:09

likelihood to be a living donor um and so we use some of this organ attitude data um and this is a multivariable

34:16

analysis um and you can kind of see here that even when controlling for race

34:23

income whether or not you worked what region of the country you lived in whether you were rural how much

34:29

knowledge you had about transplant um your religion um if you perceived the system to be unfair you

34:36

were less likely to donate um and and so you know these things have consequences for all of us

34:43

um and so when people are less likely to donate more people die we aren't the only people that show this this is a

34:50

medical distrust and it's association with the intention to donate this was a study that was done in all

34:55

African-Americans 585 African American um survey um participants um and you can

35:02

see that people's verbal intention to donate that kind of first stage of change um even when controlling for

35:09

other factors um was associated with medical distrust um and so in a cohort

35:15

of 10,000 kind of diverse subjects in our study um even looking particularly at minoritized groups this idea of not

35:23

trusting a system to be fair and just has consequences conse quences um that I

35:29

think really affect all of us am I doing on

35:37

time all right all right okay

35:42

so I have time to drain so what if I was gonna reimagine a

35:48

just transplant system um yes yes if there are questions at the

35:55

end if you want to put them in the chat or um just unmute yourself that's fine too um so if I was going to reimagine a

36:02

just transplant system I'm not going to go way out there okay with things that I

36:07

don't think are possible so this is my pragmatic wish list okay um the first

36:12

and most important thing in my mind is National transplant Equity metrics and I

36:18

hope that the whole talk has prepared you for this bullet point and you believe that this is the way to go I

36:25

hope I've convinced you that when we codify um principles ethical principles

36:31

they become true they become practiced they become adhere to um and I think

36:37

that like every other ethical principle this is the way to go um with Justice

36:42

and Equity I think that this will drive many other things um including some of

36:49

the other things I think that we practically need to help people through the system we need an acknowledgement of

36:54

social needs and health literacy we need access to care Pathways but I don't

36:59

think those things are just going to happen I think that those things will happen if we make them

37:05

happen nobody likes the word regulation um but I do believe that

37:11

thoughtful regulation um as we've talked about with an autonomy and beneficence

37:17

um can foster accountability um nurses to check with me to make sure I'm doing the right

37:22

thing resource allocation we've got whole quality committees to try to make sure we don't have too much CI um and

37:29

data driven approaches poorly designed regulation though can incentivize gameing the

37:35

system um and can really harm centers that don't have the

37:40

resources to do the things that going to be needed to meet those Equity metrics

37:46

and so it's really important that if we were to come up with national Equity metrics that people who do this for a

37:53

living who understand Equity who understand transplant are in the room to consider these things um to come up with

37:59

something that's going to be uh useful there are many examples um outside of

38:05

the ones I've given um for regulation driving um Innovation and Medicine um

38:11

and so H

38:19

oh um Hospital readmission programs uh meaningful use programs qual metrics and

38:26

dialysis centers these are all kind of regulations um that have driven um

38:33

change and and improved outcomes especially in dialysis um for patients

38:38

and so there is a um a framework for us

38:43

coming up with regulations and them driving Innovation and accountability and improving the care um of

38:49

patients um and their families what would be an example what

38:55

does that look like one example might be um dealing with catchment area mismatch

39:02

what does that mean does the transplant centers weightless reflect the demographics of the population it serves

39:08

in any way in a little bit of way you would think that would be something that we would look at but it's

39:14

not you know we don't Define service areas in any way um we've done no

39:21

there's no standard needs assessment if you work at a Federate qualified Health Center if you've ever worked at one

39:27

there's a requirement that you define your service area that you do a need assessment every three to five years for

39:33

what the needs are and that you act on the needs in the community it's reasonable if they're going to give you money it's not a reasonable um

39:40

unreasonable ask we don't do that in transplant and I think that we should um and I think that we would not ask a lot

39:47

right you do A needs assessment you outline a fiveyear plan you don't close the gap all together maybe you close it

39:53

by 10% and we incentivize it in some way transplant we don't tend to iniz we tend to

39:59

penalize um if you don't have 92% post transplant outcomes or better um then

40:05

you're no longer a blue clear Shield um Center of Distinction and and things like that and so everybody's pushing for

40:12

that good post transplant outcome and we design all these systems to make sure everybody does well in the first year it's driven a lot of innovation um but

40:20

it's a penalization system I think we have to think of ways to kind of incentivize things and and a do some um

40:25

positive parenting I think that um the first bullet point

40:34

was kind of um a national metric the second bullet point um we're kind of

40:39

coming up with social needs screening systems and access to Care Systems um this is something that we're working on

40:46

our pilot study is funded um by the ND it's a r21 um but my thought is that why

40:52

is this like why do I have to have a grant to do this like why is this not just what we do right so we spent time um engaging with

41:01

Community um gastroenterologists talking to them about what they thought they needed to get people to our transplant

41:08

center um designing a referral toolkit um and putting together a set of systems

41:15

that would help providers patients um um and GI practices and we're rolling it

41:22

out um at eight practices across Indiana but when the money's gone it's gone

41:28

right so then I have to try to apply for another Grant to do what seems like to me good

41:34

care um I'm going to skip this um and end on um the African-American transpl

41:40

Access program at Northwestern I think this is another example of a grassroot eort to improve access to transplant

41:47

this they're constantly looking for funding um it's a program that deals with distrust cultural comp competency

41:53

psychological support and health literacy is run by da Simpson she's a black um transplant surgeon at

42:00

Northwestern since she started a program in 2019 um they increased referrals um they

42:06

increase evaluations and they increase listing um of black patients in the Chicago area um and so that's not a long

42:13

time to have an impact um and she's doing this with one nurse coordinator like one social worker and herself um

42:20

and so um transplants make Hospital Systems a lot of money um and so if you

42:26

can do more transplants she's probably paid for her program um but she's

42:31

constantly looking for funding right so in conclusion um I'll leave you with these

42:38

few points um that um these are ethical principles are coded into practiceing

42:44

health care and Transplant why not Justice gender race and SCS disparities

42:50

are prevalent at every step in the care journey and insurance is really necessary uh but probably not sufficient

42:56

to fix the problem we're going to need more um than that public perception is

43:02

important um it drives a cycle of disengagement that impacts marginalized

43:08

folks but also majority folks okay so this is this a problem that it hurts

43:14

everyone and I imagine a system with smart regulation that really would

43:20

facilitate uh Community engage Solutions um and so I hope that you know one day

43:26

I'll get some to buy into that and we all aren't looking for funding for programs that really should be codified

43:33

into um our routine transplant care um I'd like to thank all the

43:39

funders and my research team and I'll pause here for any

43:51

questions you can take um questions from here in the room and then there should be Q&A questions coming to you I can't

43:57

access it myself I'm sorry otherwise I would read them to you Nick will take over your computer

44:02

and look at the Q&A online and we can see if anybody here in the room has a

44:07

question yes so there's one question in the chat let's see in residency we heard

44:14

frequently that wealthy non US citizens were able to sometimes game the organ

44:19

system by paying out a pocket for an organ transplant and bypassing the usual organ transplant protocols this in

44:25

contrast to hearing over over and over again and undocumented non- US citizens are not eligible for transplant can you

44:31

clarify if this is true or not and comment on your thoughts regarding transplant tourism oh that's a whole

44:40

talk um but um there are a few things I can kind of clarify um transplant of

44:47

non- US citizens is transplant center in state specific um there is no National policy

44:54

on transplant of non- US citizens many Centers do not do it because of the cost

44:59

because in most in many states you cannot get Medicaid as a non- US citizen

45:05

um and if you can't get Medicaid then you can't pay for transplant you can't get your post transplant meds that's been our party line here at IU is that

45:12

undocumented immigrants cannot get insurance and then therefore cannot pay for transplant so we have not been a

45:18

center who does that but there are centers in New York and in California that have funds set aside to transplant

45:26

undocumented IMM in certain cases um how do they decide it's often young moms who

45:32

have acute liver failure of pregnancy and and in cases that they can kind of get philanthropy to kind of help with um

45:39

with that but that's not something we've done at IU so a state and Transplant Center specific there's no National policy that says you can't do it um I

45:46

actually have a student who's working on a survey to get transplant center attitudes around that um because she's

45:52

on the global Health Track and what really interested in that so she's pulling together survey so stay tuned for what folks think about that in terms

45:59

of gaming the organ donation system you can't game it per se but you can list at

46:06

multiple centers if you have money um and so you can go to multiple centers in

46:11

different regions which may have different weight times and be on the list at multiple centers around the

46:17

country and some people can't afford to do that and then centers have different weight times depending on where they are

46:23

there's been a lot of policy to try to even out weight times AC across the country that haven't quite been

46:29

effective so there still are sometimes places where people used to come to Indiana for that our weight times used

46:34

to be short before some policy changes um or what you know this would be a place you want to list Indiana

46:41

Florida um not as much anymore but if you do have money you can list at

46:46

multiple

46:51

centers is this oh it is working great yeah

46:57

thanks Dr nephew for the talk extremely well organized follow like flowed very

47:02

logically appreciate it um I agree with this observation that we've done a much

47:08

better job with three of the four sort of bioethical principles and part of my

47:15

reflection on that is like as clinicians we think at an individual

47:21

level like the patient in front of us or maybe the patient the next day like much easier and so this principles are sort

47:27

of like in practice you can sort of see them and understand them more the Justice one I think my what I think is

47:35

that um it's harder right to sort of grasp as a as a clinician and not saying

47:41

that we shouldn't do it I think I'm just trying to explain maybe why this is and then I say that and think about your

47:47

final proposal as well and I'm they seem to be like large policy levers policy

47:55

solutions that you're advocating for and I wondered like to

48:00

whom would that responsibility fall on do you think I mean you're identifying the Grassroots efforts you know which

48:06

which are are sort of great but like they they found a champion right like someone to really do this right is it

48:12

the transplant centers is it the larger sort of national you know organ allocation um bodies that that sort of

48:20

do this who does this I think it's the larger organ allocation body so the United Network of organ sharing sets our

48:27

metrics for post transplant survival for weight list um outcomes the metrics that

48:33

we are judged on come from them and if you don't do well they will shut your transplant center down if you know if

48:40

you have too many people who are dying after transplant which means that your listing criteria are not right um and so

48:46

we can all well I can think about programs that this has happened to um and so I think just like they

48:52

regulate our post transplant outcomes and some our other outcomes they need to think about how to set some metrics for

49:02

this um I think that if they set the metrics transplant centers will figure

49:08

it out yeah um I don't think that they should tell us how to fix the problem I think that they should acknowledge there

49:14

is a problem worth fixing for all of us tell us you know by what margin we need

49:19

to fix it and then every transplant center is going to have different needs what they do in Chicago

49:26

um for black patients because of the patient population they have there may not work in Houston you know they're

49:33

going to be um but you will figure it out and if you go across the country all of us have different ways of managing

49:40

patients in that first year post transplant we all get to that 92% goal but everybody's kind of got a different

49:47

formula for getting there there's some principles that we share and then some things that are unique to us being

49:52

everybody being three hours away for us in Indiana because we're the only transplant center in the state that they don't have to deal with in New York or

49:58

Boston where everybody's there's so many transplant centers right so we have to think about our one-ear survival and our patient population a bit differently so

50:05

I do think I do think Innovation will happen at the transplant center level but I don't think there's impetus to

50:10

spend the money to do it and to innovate and think creatively without some regulation that comes down from our

50:16

governor bodies

50:24

yeah there's one more Yep in my work with transplant teams I have noticed a unique dual obligation that many

50:30

clinicians do not feel or feel much l strongly um they seem to feel that traditional obligation to acting in best

50:36

interest of patients but also feel a strong obligation to acting as stewards of scarce resource um can you speak um

50:46

about your experience with this tension yeah um so you know we as

50:53

transplant um providers we are dealing with a scarce resource and you want to

50:58

give a scarce resource to the people who you think are going to do best with it survive the most with it um and that may

51:04

not be someone who's got poor social support or who are struggling in some of these areas um post transplant in your

51:11

mind um how I deal with it um is I let the transplant team deal with that when

51:17

I'm talking about my individual patient I am advocating for that patient within

51:22

reason okay like I'm not saying that I'm like transplanting like just any body but within reason my commitment as that

51:31

patient's doctor is to that patient not to the system and everybody else is on

51:36

the committee can think about the system um but when I'm presenting my patient I'm presenting my patient to get a

51:43

transplant um and so I try not to think about who's not getting a transplant

51:48

because I feel like that's not my job for an individual patient and then I let all my colleagues think about that it's

51:56

time for one more question we're a little bit over is there another one online no I don't think so to our final

52:02

question maybe maybe we should wrap up because it's 103 do you mind no sure we're g go ahead and wrap up because

52:07

we're past time thank again to thank you so much and um we'll let you ask your

52:13

question individually after thank you so much Dr npew

okay so for those of you who saw my original Talk title don't be disappointed um we will be covering

0:11

those topics um but as I got to putting together the slides and really thinking about what I wanted to say to you today

0:18

I thought this was a more fitting title what about Justice um so before I delve

0:24

into kind of some of the content that I want to talk about today I'd like to give you a little bit background of how

0:31

I got interested in this topic and how I came to be someone who studies Justice and health and

0:39

Equity maybe I want to do that I can get my slides to move

0:47

forward let's try that [Music]

1:04

all right now my slides are moving forward now um so I uh have a screenshot

1:11

here um of a very young picture of me um from

1:16

2010 um that top picture is me and my happy bright and unjaded face as a fresh

1:23

graduate getting my match letter to man's greatest hospital um and that

1:29

picture below um is a picture of my head shot again bright naive happy excited ready to go

1:36

into the world um and so as a medical student at Case Western Cleveland Clinic

1:42

learner College of Medicine um my third year I was pretty sure that I wanted to do GI and hepatology and so I was doing

1:49

a rotation and one of the residents said you know one of your patients is going

1:54

to be presented today in liver transplant committee meeting why don't you go to the committee meeting and I

2:00

said okay I said I think he's just trying to get rid of me but it may be interesting okay so I went I sat in the

2:06

back and I came in with this kind of idea of what I expected to happen I

2:11

expected like a big screen to come down and for like all the names to go up on the board and for everybody's clinical

2:18

information to come up and there to be this rigorous discussion about how we can get people to

2:24

transplant and that wasn't what it was um my expectations did did not get met

2:31

um and I can say since that time I have been to many transplant committee me at different centers and there was nothing

2:38

wrong with the transplant committee meeting to happen at Case Western but it was not what I expected it was people

2:44

eating lunch people answering Pages people saying why people weren't eligible without thinking about

2:50

Solutions it was what to me seemed like very casual uh for something so

2:56

substantial um and my patient was not listed he was thought that he did not have enough social support and it was

3:02

given very short discussion um and I was shocked I left that committee meeting

3:07

and I remember uh telling my senior I can't believe this is how committee meetings go was this some type of

3:13

anomaly nobody seemed to be trying to help this patient and he just looked at me and and shook his head um and then I

3:20

had that same conversation with family and friends afterwards and everybody nobody was quite sure why I was so

3:25

bothered but I was very bothered by the whole thing and so I said well I wanna I

3:30

want to be able to talk about this and use some terms and talk about these things that I'm feeling and experiencing

3:35

and this fairness that I feel like is not there in some kind of educated way and so I started Googling um liver

3:43

transplant and fairness and I I came ac across some things about art kathan and

3:48

other folks and I said um maybe if I take a bioethics class I'll be able to

3:53

kind of Express what I'm feeling and talk about it um in a more meaningful way so I took a bio ethics class and a

4:00

bioethics class turned into a bioethics masters um and that's how I landed in

4:06

this space um really wanting to be able to express what I was seeing the

4:12

problems I was seeing in some type of way that wasn't just emotional it wasn't just this doesn't seem like it's right

4:18

um and that's how I became kind of or got on this path of exploring um Justice

4:24

and social justice from a bioethics framework so I learned learned a lot of

4:30

different ethical constructs in transplantation um as a bioethics

4:35

student um that did arm me with some tools to write a lot of good editorials and so we'll we'll run through some

4:42

ethical constructs um in uh transplant I learned about scarce resource allocation

4:48

right and and this idea that there's not enough um to go around and you've got to

4:53

think about how to distribute them fairly um and effectively um and I actually wrote my kind of Master thesis

5:00

around this concept of scarce resource allocation and kidney uh

5:06

transplantation I learned about distributive justice um this concept that even in the setting of scarce

5:12

resource allocation um you have to still understand how the burdens and the

5:18

benefits in healthcare are allocated and distributed amongst all individuals and

5:23

so that seemed to get at a bit of what I was feeling in that committee meeting that yes there's a scarce resource but

5:29

can we ensure um that some people aren't bearing all of the

5:35

burdens autonomy um of course was something that I learned about um that

5:40

you know people have to make informed decisions about whether or not they want to partake in healthcare even transplant

5:46

it's a life-saving Endeavor but everybody doesn't want to do that and that's okay um and there's going to be some people who need to be able to

5:53

express that kind of autonomy um that they aren't interested in transplant for whatever their reasons may be

6:00

he learned about how to be a benefit right um to patients and really thinking

6:06

about transplant and the people who are going to have the best survival and so that becomes a big topic and a big Focus

6:13

that we'll talk about more in transplant and of course we want to do no harm um we want to pick the people

6:22

who are going to have the best outcomes and then finally um some of the concepts

6:27

that I thought about were moral distress um and so I think sitting in that meeting I felt a bit distressed um some

6:34

discomfort um as a clinician um and feeling like there was some injustice and that there was nothing that I could

6:40

do about it and so I was armed with this framework um and and I've written um

6:45

editorials and I've I've thought about these Concepts and and how they applied to the patient that I saw in medical

6:50

school and many of the patients that I see today but I still have to say that even over a decade later I'm left with

6:59

this question it doesn't burn me in the same way it did as a medical student um but I still feel like of the four major

7:07

ethical principles um in transplant and in health care autonomy beneficence

7:14

Nance and Justice why does Justice see receive the least

7:20

attention why is Justice the stepchild of all of the ethical principles and

7:27

what can we do about that and what would it look like what would

7:33

Healthcare look like what would transplant look like what would the world look like if Justice were treated

7:40

as a equal ethical principle in transplantation and so armed with kind

7:46

of the framework about how to think about these things this is the question that drives me every day this is why I

7:52

get up every morning this is why I do the work that I do this is why I apply for grants in the face of executive

7:58

orders because I want to know what would the world look like if people cared as

8:04

much about justice as they did about autonomy so these are objectives that we

8:11

will cover today we will um examine those four ethical principles and we

8:18

will talk about how they're coded into health care and Transplant um and we'll

8:23

talk about how Justice really is not we will then review some of the disp

8:29

ities in liver transplantation and highlight some key access and outcome issues that I think happen as a result

8:36

of really our lack of focus on Justice and then we'll talk about the

8:42

consequences of a failure to deal with our justice issue and because I think

8:48

that there's this idea that not dealing with Justice and not dealing with health and Equity is somebody else's problem um

8:55

but Injustice has consequences okay um and so we're going to talk about public

9:01

perception in Justice and the consequences in organ donation of our lack of focus about uh justice and

9:09

trust and then we're going to dream and talk about what if we were to

9:15

reimagine a just transplant system if I could have some of the things that I

9:21

would like that I would think would move us away from where we are now what they look like um and so we'll end on a on a

9:27

high note but let's start with talking about some of the uh ethical principles in

9:34

healthcare and Transplant and how they are coded um in a part of our kind of

9:40

framework in a way that I think Justice is not so autonomy is a patient's right to

9:47

make their own medical decisions we all understand it and it is legally

9:52

protected okay um the principle is reinforced through informed consent

9:58

shared decision making um if I leave a endoscopy room and I have forgotten I've

10:06

talked to the patient about the procedure I've explained it but for some reason I didn't get their signature and

10:11

I didn't sign the consent form there's five nurses chasing me down the hallway to make sure that those consent forms

10:18

get signed before I put that scope in the patient okay um and so we have

10:24

processes in place to make sure that patients autonomous is documented um

10:31

there are many of us in ethics who spend our career reading about writing about

10:37

talking about informed consent um if you want to overcome someone's autonomy what

10:43

are the situations where that's possible right um so there is um this is not

10:49

something that's just ethical though right this is legally mandated um and there are many processes in place across

10:55

all of healthcare to ensure that people's um autonomy is not violated um

11:01

and so if you would violate someone's autonomy and you know the accreditation folks come and see that there's consent

11:08

forms that are dated and timed after I did the procedure we get dinged our

11:13

endoscopy Suite gets dinged and if you have too many of those that you don't correct you can lose your privileges and

11:19

if it lands on one physician that they aren't getting you know adequate informed consent you know that could be

11:26

a lawsuit right so these are things that are uh ethical principles that we talk about and we write about and we

11:32

pontificate about but they're also regulated um in our laws in our practices at all layers of healthcare to

11:40

make sure that they're respected and I have to say uh you'll see where I'm going with this Justice

11:46

really not so much right um

11:52

nances uh Do no harm um it is also um a

11:57

core ethical principle right um a core principle in medicine that we learn about in medical school um that we

12:03

should do no harm um and we don't want to hurt patients um but it's not just something that we take in our Oaths and

12:10

that we talk about when we get you know um we walk across the stage um to

12:15

receive our kind of you know cap and gown um there are many safety checks to

12:20

make sure that we do no harm to patients right um and so there's infection control protocols if you're on impatient

12:27

service everybody wants to make sure you a gown did you walk out of the room without washing your hands there are

12:32

people who police to make sure that you are not going to pass C death from Patient to Patient to Patient um this is

12:39

something that um is happening in every hospital across the country um there are medication Safety Systems so that we

12:46

scan medicines and make sure that patients are getting the right doses at the right time there's surgical

12:51

checklist their time outs before I can put an endoscopy scope into a patient we have to do a timeout and confirm that

12:58

this is the right patient getting the right procedure and there are many people to make sure that I don't skip

13:04

past that and how many surgeons and proceduralist like me would skip past

13:09

that if there weren't checks in place right it's like ah I know this is the right patient right but it never happens I have never scoped the patient without

13:15

a timeout because there are processes in place to make sure the doct nephew gets

13:21

this done okay um and so a failure to uphold these things if you've got SE if

13:27

running rampant through your hospital if you've got you know infections you will not be

13:33

reimbursed your hospital just will not be reimbursed um and within transplant

13:39

similarly um you know the Mel score was a system is designed in some ways to

13:44

minimize harm right the meld score for those of you who don't do transplant is a allocation score um it's a score that

13:51

tells us how sick the liver is it helps us decide to decide who moves to the top um of a transplant list um and so

13:58

allocation is design to um to take the sickest people first um and it's upheld

14:04

through laws and policies um to make sure that we're abiding by the Mel score and the Mel score is what we're using to

14:09

alligate uh organs um and so um all of these protocols that are in place um

14:16

safety protocols around medicine around transplant around surgical Protocols are

14:22

all put in place so that we don't harm patients um and it's not just left to I

14:28

hope that Dr nephew doesn't harm patients um this is uh there's lots of

14:36

systems to make sure that I don't do

14:42

that you also have an obligation to not just not harm patients right we have a a

14:48

obligation people don't pay us for us just not to harm them they want us to be a benefit to them right um and so

14:54

benefices says that Healthcare Providers are are supposed to benefit p Pati and really act in their best interest and we

15:01

we take the hypocritic oath and that's a really big part um of why we do what we do but again it's not just an oath okay

15:09

they are evidence-based um protocols that guide everything we do um they guide how we

15:15

treat cancer how we treat infection how we treat preclampsia um and if it's

15:21

discovered that you're not following evident evidence-based protocols you can lose your license right um because not

15:27

only are you not supposed to hurt people you're supposed to be providing care that's in their best interest you're

15:32

supposed to be benefiting them following practice guidelines of the current best data and so we meet in groups to make

15:39

sure that we all are following the same practices that you know everybody in our group is doing pretty much the same

15:46

thing um and so these are important um parts of benefiting patients in

15:51

transplant we do the same thing we have listing criteria um that explicitly kind

15:56

of help us to identify the patients we're going to benefit the most from transplant so these are things again um

16:03

that are regulated codified in medical care to ensure we do the right

16:09

thing what about Justice well I would say there's

16:15

lawlessness Anarchy um it's all over the place right

16:20

um there's uh not a similar understanding uh or codification in

16:27

medicine that this principle is anywhere near as important as autonomy um now

16:33

malus and uh beneficence and so what kind of

16:39

structural implementation do we have of Justice in US Healthcare and Transplant system there's been some some Oaths that

16:46

talk about Justice okay so the Declaration of Geneva um the original

16:51

one in 1948 and the revised one in 2017 is probably the closest kind of code in

16:57

medicine that we has that really gets that Justice um that it says I will not permit considerations of age disease

17:04

disability Creed ethnic origin gender nationality political affiliation race

17:10

sex or social standing or any other factor to intervene between my duty and my patient and so I think that's pretty

17:17

explicit kind of a justice statement the modern hypocracy

17:25

will remember that I remain a member of society with a special obligation to

17:31

allow all my fellow human uh to all my fellow human beings those of sound mind

17:37

and body as well as the infirm maybe that's a justice statement it's not quite as clear um as the Declaration of

17:44

Geneva but maybe that's a Justice um statement um but beyond that um unlike

17:50

the other ethical principles this is rather debated and not embedded it's

17:56

talked about it's discussed it's argu argued it's executive ordered but it is

18:01

not um embedded in our practice um and there really no systemic safeguards to

18:07

really ensure or guarantee that anybody gets Equitable care or Equitable access to

18:12

transplantation and so Justice is this kind of idea if you've ever seen this Giving Tree right that um everybody has

18:20

access to the same apples everybody's got the same tools um and then there's this perfect system where everything is

18:27

equal um but unfortunately that's not the world we live in we live in a world

18:32

um of inequality um where there's unequal access to opportunity um and some people have privilege and some

18:38

people don't and people don't have ladders and everybody's trying to get to the same place um but there's really no

18:43

safeguards to ensure that that can that can happen um and so I hope I've I've

18:50

got you thinking even if I haven't convinced you um that the ethical principles that we all study they mean

18:57

something in healthcare they they're codified they are part of why we do what we do um and they are abided by and irbs

19:06

and everybody make sure that we do a good job um but not so much with Justice um and I think that that's unfortunate

19:11

and I think that's why we are where we are today so we're going to talk a little bit about where we are today um

19:18

with disparities and liver transplantation um because I think this is a result of the lack of um focus um

19:27

code requirement um um in this space and so we're just

19:32

kind of out here willy-nilly and that really doesn't get us anywhere um so therosis um is a pretty

19:40

prevalent condition um it was 0.6 per 100,000 in the 90s now we're at

19:48

132.5 per 100,000 in 2017 and you can just see that this barograph is steadily

19:54

inching up and so while therosis may not be a problem that comes to your mind

19:59

like heart disease or breast cancer but it is on the Rise um in the setting of

20:05

alcohol Ade epidemic and obesity epidemic we expect um that mortality from therosis will continue to rise over

20:12

the next decade and so this has becoming a real serious public health issue it's

20:17

always been a public health issue but it's becoming more to the attention of folks who may have been focused on other comities than

20:25

before this is a a complicated figure if you're not of hepatologist but there's really just one thing I want to point

20:31

out um and that is that if you have decompensated liver disease liver

20:36

disease with complications your fiveyear survival is 85% um or your fiveyear mortality excuse

20:43

me is 85% um so this not only is a condition that is on the rise it is a quite more bit condition um and so um

20:51

and unlike other chronic diseases like kidney transplant where you can go on

20:56

dialysis and live live a fairly decent life perhaps or heart failure where you

21:02

may even be able to get a elad and that can help pump your heart for for several years um in liver transplantation

21:10

there's really no other solution you either get transplanted or you die um there's really no Bridge or temporizing

21:17

measure um and so I think when we think about equity in solid organ transplantation in liver disease is

21:23

particularly important because of that lack of bridging therapy

21:29

we're doing more liver transplants than we've ever done before um here at IU we did I think 212 or so liver transplants

21:36

this year when I started here um eight years ago I think we were doing 120 so

21:41

we are doing more and more liver transplants not just at IU but around the country because of some of the

21:46

advances in technology but as you can see in this figure um that despite the fact that

21:52

we're doing more liver transplants which is in the red look how high the weight list is right so just all these people

21:59

um who are on the weight list um who will not get transplanted and this is just the people on the weight list right

22:05

so we're not even talking about the people who never make it to the weight list because of um barriers and access to care um so the burden of people who

22:12

are dying without transplant is probably a lot higher than what um this figure um can um

22:19

display disparities and access to transplant happen um not just at the weight listing space um they happen

22:26

along the whole care Cascade this this is a figure that I like from n the national um Academy of Science

22:33

engineering and Medicine um this is a report they did on transplantation um and it just takes you through some of

22:39

the steps that people don't think about um as much when they think about solid organ transplantation because a lot of

22:45

the disparities start all the way at the diagnosis and disease management step some people might not have needed a

22:50

transplant if their hepsy had been diagnosed right um and treat it because we can cure heepsy now um so awareness

22:56

and education and all the things that lead up to referral evaluation and then

23:01

weight listing doesn't come till here and so much of the focus around Justice and equity and transplantation um if

23:08

there has been any has been at this step right but there are all of these steps that happen before and as we think about

23:13

preventative care and um chronic disease and organ transplantation there's so many things Upstream that we could do um

23:20

in my mind um to kind of help this process I'm going to share with you a

23:27

few um parities for uh some groups so that you can kind of get a context of or

23:32

idea about where we are um starting off with women um and this figure just describes kind of the steps in the care

23:39

Cascade from pre-evaluation evaluation weight listing and a post liver transplant outcomes um and you can see

23:47

that that print came out a little smaller than I expected but um women um are less likely um to um to move from

23:56

diagnosis to evaluation from liver transplant um a study at the University in Michigan showed that women um were

24:04

less likely to be listed even when they in evaluation often due to active substance use issues than men um at the

24:10

weight listing step women have a 50 to 30% higher weight listing mortality than

24:15

men um and are 20 to 30% less likely to undergo liver transplantation and then

24:21

post- liver transplant women have lower quality of life scores um difficulty with psychological adjustment um

24:27

distress um personal um function and so there disparities for women at every step in a

24:34

care Cascade that could be explored when you think about um how

24:39

long we known about disparities and liver disease um or gender disparities and liver disease the sex inity was

24:46

first described by simply moand at Duke in 2008 and if you were to take how long

24:51

we known about it before we did anything about it I think it's been maybe a year since we made a modification to the meld

24:58

score to correct for um to give women a little bit of extra boost okay that just

25:04

happened but we identified this SP in 2008 uh oh uh

25:10

oh um assuming that we had done something about this many years ago 800 women probably would have um still been

25:18

alive and so doing nothing about these disparities and kind of just sitting on them and hoping that they're going to

25:23

get better on their own without changing metal scores Without Really changing policies um is really um life-altering

25:31

and deadly um for the populations who are at a disadvantage Beyond gender I'll show you

25:37

a little race and sces data right here from IU um we looked at over 3,500

25:43

patients who were referred to IU for liver transplantation evaluation between 2011 and

25:48

2018 um you can see the demographics of the people who are referred um 41%

25:55

Medicaid uh 12.5% rural 39% women so our

26:00

referral um patient population in many ways does mirror the population of

26:06

Indiana except for by race all right so 12% of hooers are black and only 6% of

26:12

those who are referred um were black and understanding that um there's a higher

26:17

burden of liver disease in many racial and ethnic bity groups we probably would expect to see over 12% just like in

26:23

Medicaid 40% of hoers don't have Medicaid I think it's somewhere in a 20 to 30 per range but that population has

26:29

more uh liver disease so as expected you see that they're over represented and so you would expect to see that uh probably

26:36

in Rural and in Black patients when we looked at who was dying

26:41

during eval um for transplantation uh we didn't see race or gender differences

26:47

but we did see that coming from a a neighborhood that experiences poverty um made you 50% more likely um to die

26:54

during transplant evaluation this was when controlling for race gender um individual social economic status

27:00

disease comorbidity liver disease severity and this still stood the test of a robust um

27:07

evaluation um and then on the weight list we saw the weight listing um the neighborhood poverty was also associated

27:13

with weight listing and so when people thinking about what are the solutions how do you

27:19

fix um some of these disparities that I'm talking about one of the thing that comes to your mind is

27:27

um that National policies Medicaid expansion um I think we have a tendency

27:33

to really want to push the buck on Justice to somebody else okay um and so

27:39

um that's how I thought when I first started doing this work I said I want to look at and see you know how to Medicaid

27:45

expansion help these problems because that's the way to fix um Health disparities um and so what we found um

27:52

when we looked at the impact of Medicaid expansion on access to the weight list for transplantation um we can see that

27:59

in the kind of grayish blue bars um that there was some small increase in Hispanic patients um listing um but

28:06

there was not the similar increase in white or black patients and so um while

28:12

policy is important it is necessary um National policies around Insurance are

28:17

not sufficient to deal with the justice issues that we have in

28:23

transplantation some people would say well our Health Care system is just not as as robust well I can tell you they

28:30

have the same problem in Canada okay so this is Canadian data looking at area level income um and as association with

28:38

liver transplant access um this is a populationbased cohort over a 20year period of individuals from Ontario

28:45

Canada um and what they found was that living in a poor neighborhood once again was associated with um um a 50% less

28:54

likelihood almost of being transplanted and this is in a place where they have Universal healthare and so again I'm not

29:01

knocking Universal healthare I don't want to or Medicaid expansion I think that these are very important programs

29:07

and that they are necessary for us to do the additional work we need to do to codify justice but they aren't

29:13

sufficient and so this idea that if they just do more in Washington this problem would go away is likely not true um

29:20

there's more that's going to have to be done than just giving people Universal healthare um to deal with the inequities

29:26

that we have here um and trans in healthare in

29:31

general so what does the public think about our Justice problem maybe it's just me right maybe I'm the only person

29:39

who has a problem with Justice maybe it's just me the seed was planted as a medical student and nobody else is

29:45

bothered by this that's not true okay um so the public doesn't trust us either

29:52

okay uh so this is data from the 2019 National survey of organ donation attitudes and practice practices it's

29:58

over 10,000 participants in this survey um they over sample and make sure that they've got demographic representation

30:06

of Asian Americans Native Americans black Americans it's a very well done study um and so if you look um at the

30:14

number of folks who believe our donation system is fair it's about

30:20

66% maybe we think that's a win but if my you know I don't know that's like my

30:25

my son coming home and telling me I got a 66 % it's like 40% of people don't

30:31

think our distribution or donation system is fair I would say we have some work to do there um if you ask people do

30:38

you have an equal chance of getting an organ if you're rich or poor about 52% of people believe that to be true so 50%

30:45

of people don't believe you have an equal chance of getting an organ if you're poor okay and then more striking

30:51

and maybe hard to read um is that uh 48% of people now believe that minorities

30:57

are less likely to receive an organ transplantation and you can see the increase they do this study every five

31:03

years or so so you can see that went from 29 to 30 to 48% we aren't just

31:09

asking minorities this question they ask everybody this question everybody knows the system isn't right right so people

31:15

recognize and perceive the Injustice we're not like hiding back here in healthcare um they recognize that the

31:22

system isn't quite right why is trust important in Oregan

31:29

allocation this is arap quote I don't believe everything he says but I think this is a good one um the values of

31:35

altruism and autonomy the foundations of organ procurement rest on the presumption that organs which are given

31:41

freely voluntarily and altruistically will distributed in a fair and impartial

31:46

manner to those in need any policies practices or activities that suggest otherwise and Peril the entire

31:53

Enterprise of voluntary and alteristic organ donation and when the public

31:59

declines uh trust declin so does Oregon donation rates and that's been shown in

32:05

several studies and so the Public's perception around organ

32:12

transplantation and their and perception of inequity and lack of fairness it just

32:18

keeps that organ donation number low you see how many people are on the weight list right if we want people to really

32:23

buy into the system then we've got to get over people's um perceived um I

32:29

don't even want to call it perceived their recognition of the injustices in the

32:35

system and so this is something that I in my mind I just describe as kind of a

32:41

vicious cycle um this Justice trust cycle right um so when Justice is embedded into policies and practices it

32:48

builds trust people trust the system they perceive it to be fair they think

32:54

transplant is Equitable and all is well so when Justice strengthens trust trust

33:01

increases participation and organ donation and then precip uh participation reinforces Justice because

33:08

if everybody's involved in the system everybody's making recommendations about how to move things forward you got community engagement and you just go

33:15

around this nice pretty kind of Justice trust um cycle if things are going right

33:21

when things are not going right the cycle gets broken right um so breaking a cycle through unequitable policies and

33:28

uh practices leads to distrust disengagement people aren't a part of

33:33

the process they don't want to donate they aren't a part of making rules about the uh the system because they don't

33:38

feel like they're they're even consider um and then you get whing disparities um so I don't think we're in the left box

33:46

unfortunately when it comes to transplant I think that this cycle um is becoming broken and it's evidence as 49%

33:54

of Americans recognizing that that really there's some infer unfairness is happening we looked at this um question

34:03

of whether or not um people's perceived inequality when infect uh their

34:09

likelihood to be a living donor um and so we use some of this organ attitude data um and this is a multivariable

34:16

analysis um and you can kind of see here that even when controlling for race

34:23

income whether or not you worked what region of the country you lived in whether you were rural how much

34:29

knowledge you had about transplant um your religion um if you perceived the system to be unfair you

34:36

were less likely to donate um and and so you know these things have consequences for all of us

34:43

um and so when people are less likely to donate more people die we aren't the only people that show this this is a

34:50

medical distrust and it's association with the intention to donate this was a study that was done in all

34:55

African-Americans 585 African American um survey um participants um and you can

35:02

see that people's verbal intention to donate that kind of first stage of change um even when controlling for

35:09

other factors um was associated with medical distrust um and so in a cohort

35:15

of 10,000 kind of diverse subjects in our study um even looking particularly at minoritized groups this idea of not

35:23

trusting a system to be fair and just has consequences conse quences um that I

35:29

think really affect all of us am I doing on

35:37

time all right all right okay

35:42

so I have time to drain so what if I was gonna reimagine a

35:48

just transplant system um yes yes if there are questions at the

35:55

end if you want to put them in the chat or um just unmute yourself that's fine too um so if I was going to reimagine a

36:02

just transplant system I'm not going to go way out there okay with things that I

36:07

don't think are possible so this is my pragmatic wish list okay um the first

36:12

and most important thing in my mind is National transplant Equity metrics and I

36:18

hope that the whole talk has prepared you for this bullet point and you believe that this is the way to go I

36:25

hope I've convinced you that when we codify um principles ethical principles

36:31

they become true they become practiced they become adhere to um and I think

36:37

that like every other ethical principle this is the way to go um with Justice

36:42

and Equity I think that this will drive many other things um including some of

36:49

the other things I think that we practically need to help people through the system we need an acknowledgement of

36:54

social needs and health literacy we need access to care Pathways but I don't

36:59

think those things are just going to happen I think that those things will happen if we make them

37:05

happen nobody likes the word regulation um but I do believe that

37:11

thoughtful regulation um as we've talked about with an autonomy and beneficence

37:17

um can foster accountability um nurses to check with me to make sure I'm doing the right

37:22

thing resource allocation we've got whole quality committees to try to make sure we don't have too much CI um and

37:29

data driven approaches poorly designed regulation though can incentivize gameing the

37:35

system um and can really harm centers that don't have the

37:40

resources to do the things that going to be needed to meet those Equity metrics

37:46

and so it's really important that if we were to come up with national Equity metrics that people who do this for a

37:53

living who understand Equity who understand transplant are in the room to consider these things um to come up with

37:59

something that's going to be uh useful there are many examples um outside of

38:05

the ones I've given um for regulation driving um Innovation and Medicine um

38:11

and so H

38:19

oh um Hospital readmission programs uh meaningful use programs qual metrics and

38:26

dialysis centers these are all kind of regulations um that have driven um

38:33

change and and improved outcomes especially in dialysis um for patients

38:38

and so there is a um a framework for us

38:43

coming up with regulations and them driving Innovation and accountability and improving the care um of

38:49

patients um and their families what would be an example what

38:55

does that look like one example might be um dealing with catchment area mismatch

39:02

what does that mean does the transplant centers weightless reflect the demographics of the population it serves

39:08

in any way in a little bit of way you would think that would be something that we would look at but it's

39:14

not you know we don't Define service areas in any way um we've done no

39:21

there's no standard needs assessment if you work at a Federate qualified Health Center if you've ever worked at one

39:27

there's a requirement that you define your service area that you do a need assessment every three to five years for

39:33

what the needs are and that you act on the needs in the community it's reasonable if they're going to give you money it's not a reasonable um

39:40

unreasonable ask we don't do that in transplant and I think that we should um and I think that we would not ask a lot

39:47

right you do A needs assessment you outline a fiveyear plan you don't close the gap all together maybe you close it

39:53

by 10% and we incentivize it in some way transplant we don't tend to iniz we tend to

39:59

penalize um if you don't have 92% post transplant outcomes or better um then

40:05

you're no longer a blue clear Shield um Center of Distinction and and things like that and so everybody's pushing for

40:12

that good post transplant outcome and we design all these systems to make sure everybody does well in the first year it's driven a lot of innovation um but

40:20

it's a penalization system I think we have to think of ways to kind of incentivize things and and a do some um

40:25

positive parenting I think that um the first bullet point

40:34

was kind of um a national metric the second bullet point um we're kind of

40:39

coming up with social needs screening systems and access to Care Systems um this is something that we're working on

40:46

our pilot study is funded um by the ND it's a r21 um but my thought is that why

40:52

is this like why do I have to have a grant to do this like why is this not just what we do right so we spent time um engaging with

41:01

Community um gastroenterologists talking to them about what they thought they needed to get people to our transplant

41:08

center um designing a referral toolkit um and putting together a set of systems

41:15

that would help providers patients um um and GI practices and we're rolling it

41:22

out um at eight practices across Indiana but when the money's gone it's gone

41:28

right so then I have to try to apply for another Grant to do what seems like to me good

41:34

care um I'm going to skip this um and end on um the African-American transpl

41:40

Access program at Northwestern I think this is another example of a grassroot eort to improve access to transplant

41:47

this they're constantly looking for funding um it's a program that deals with distrust cultural comp competency

41:53

psychological support and health literacy is run by da Simpson she's a black um transplant surgeon at

42:00

Northwestern since she started a program in 2019 um they increased referrals um they

42:06

increase evaluations and they increase listing um of black patients in the Chicago area um and so that's not a long

42:13

time to have an impact um and she's doing this with one nurse coordinator like one social worker and herself um

42:20

and so um transplants make Hospital Systems a lot of money um and so if you

42:26

can do more transplants she's probably paid for her program um but she's

42:31

constantly looking for funding right so in conclusion um I'll leave you with these

42:38

few points um that um these are ethical principles are coded into practiceing

42:44

health care and Transplant why not Justice gender race and SCS disparities

42:50

are prevalent at every step in the care journey and insurance is really necessary uh but probably not sufficient

42:56

to fix the problem we're going to need more um than that public perception is

43:02

important um it drives a cycle of disengagement that impacts marginalized

43:08

folks but also majority folks okay so this is this a problem that it hurts

43:14

everyone and I imagine a system with smart regulation that really would

43:20

facilitate uh Community engage Solutions um and so I hope that you know one day

43:26

I'll get some to buy into that and we all aren't looking for funding for programs that really should be codified

43:33

into um our routine transplant care um I'd like to thank all the

43:39

funders and my research team and I'll pause here for any

43:51

questions you can take um questions from here in the room and then there should be Q&A questions coming to you I can't

43:57

access it myself I'm sorry otherwise I would read them to you Nick will take over your computer

44:02

and look at the Q&A online and we can see if anybody here in the room has a

44:07

question yes so there's one question in the chat let's see in residency we heard

44:14

frequently that wealthy non US citizens were able to sometimes game the organ

44:19

system by paying out a pocket for an organ transplant and bypassing the usual organ transplant protocols this in

44:25

contrast to hearing over over and over again and undocumented non- US citizens are not eligible for transplant can you

44:31

clarify if this is true or not and comment on your thoughts regarding transplant tourism oh that's a whole

44:40

talk um but um there are a few things I can kind of clarify um transplant of

44:47

non- US citizens is transplant center in state specific um there is no National policy

44:54

on transplant of non- US citizens many Centers do not do it because of the cost

44:59

because in most in many states you cannot get Medicaid as a non- US citizen

45:05

um and if you can't get Medicaid then you can't pay for transplant you can't get your post transplant meds that's been our party line here at IU is that

45:12

undocumented immigrants cannot get insurance and then therefore cannot pay for transplant so we have not been a

45:18

center who does that but there are centers in New York and in California that have funds set aside to transplant

45:26

undocumented IMM in certain cases um how do they decide it's often young moms who

45:32

have acute liver failure of pregnancy and and in cases that they can kind of get philanthropy to kind of help with um

45:39

with that but that's not something we've done at IU so a state and Transplant Center specific there's no National policy that says you can't do it um I

45:46

actually have a student who's working on a survey to get transplant center attitudes around that um because she's

45:52

on the global Health Track and what really interested in that so she's pulling together survey so stay tuned for what folks think about that in terms

45:59

of gaming the organ donation system you can't game it per se but you can list at

46:06

multiple centers if you have money um and so you can go to multiple centers in

46:11

different regions which may have different weight times and be on the list at multiple centers around the

46:17

country and some people can't afford to do that and then centers have different weight times depending on where they are

46:23

there's been a lot of policy to try to even out weight times AC across the country that haven't quite been

46:29

effective so there still are sometimes places where people used to come to Indiana for that our weight times used

46:34

to be short before some policy changes um or what you know this would be a place you want to list Indiana

46:41

Florida um not as much anymore but if you do have money you can list at

46:46

multiple

46:51

centers is this oh it is working great yeah

46:57

thanks Dr nephew for the talk extremely well organized follow like flowed very

47:02

logically appreciate it um I agree with this observation that we've done a much

47:08

better job with three of the four sort of bioethical principles and part of my

47:15

reflection on that is like as clinicians we think at an individual

47:21

level like the patient in front of us or maybe the patient the next day like much easier and so this principles are sort

47:27

of like in practice you can sort of see them and understand them more the Justice one I think my what I think is

47:35

that um it's harder right to sort of grasp as a as a clinician and not saying

47:41

that we shouldn't do it I think I'm just trying to explain maybe why this is and then I say that and think about your

47:47

final proposal as well and I'm they seem to be like large policy levers policy

47:55

solutions that you're advocating for and I wondered like to

48:00

whom would that responsibility fall on do you think I mean you're identifying the Grassroots efforts you know which

48:06

which are are sort of great but like they they found a champion right like someone to really do this right is it

48:12

the transplant centers is it the larger sort of national you know organ allocation um bodies that that sort of

48:20

do this who does this I think it's the larger organ allocation body so the United Network of organ sharing sets our

48:27

metrics for post transplant survival for weight list um outcomes the metrics that

48:33

we are judged on come from them and if you don't do well they will shut your transplant center down if you know if

48:40

you have too many people who are dying after transplant which means that your listing criteria are not right um and so

48:46

we can all well I can think about programs that this has happened to um and so I think just like they

48:52

regulate our post transplant outcomes and some our other outcomes they need to think about how to set some metrics for

49:02

this um I think that if they set the metrics transplant centers will figure

49:08

it out yeah um I don't think that they should tell us how to fix the problem I think that they should acknowledge there

49:14

is a problem worth fixing for all of us tell us you know by what margin we need

49:19

to fix it and then every transplant center is going to have different needs what they do in Chicago

49:26

um for black patients because of the patient population they have there may not work in Houston you know they're

49:33

going to be um but you will figure it out and if you go across the country all of us have different ways of managing

49:40

patients in that first year post transplant we all get to that 92% goal but everybody's kind of got a different

49:47

formula for getting there there's some principles that we share and then some things that are unique to us being

49:52

everybody being three hours away for us in Indiana because we're the only transplant center in the state that they don't have to deal with in New York or

49:58

Boston where everybody's there's so many transplant centers right so we have to think about our one-ear survival and our patient population a bit differently so

50:05

I do think I do think Innovation will happen at the transplant center level but I don't think there's impetus to

50:10

spend the money to do it and to innovate and think creatively without some regulation that comes down from our

50:16

governor bodies

50:24

yeah there's one more Yep in my work with transplant teams I have noticed a unique dual obligation that many

50:30

clinicians do not feel or feel much l strongly um they seem to feel that traditional obligation to acting in best

50:36

interest of patients but also feel a strong obligation to acting as stewards of scarce resource um can you speak um

50:46

about your experience with this tension yeah um so you know we as

50:53

transplant um providers we are dealing with a scarce resource and you want to

50:58

give a scarce resource to the people who you think are going to do best with it survive the most with it um and that may

51:04

not be someone who's got poor social support or who are struggling in some of these areas um post transplant in your

51:11

mind um how I deal with it um is I let the transplant team deal with that when

51:17

I'm talking about my individual patient I am advocating for that patient within

51:22

reason okay like I'm not saying that I'm like transplanting like just any body but within reason my commitment as that

51:31

patient's doctor is to that patient not to the system and everybody else is on

51:36

the committee can think about the system um but when I'm presenting my patient I'm presenting my patient to get a

51:43

transplant um and so I try not to think about who's not getting a transplant

51:48

because I feel like that's not my job for an individual patient and then I let all my colleagues think about that it's

51:56

time for one more question we're a little bit over is there another one online no I don't think so to our final

52:02

question maybe maybe we should wrap up because it's 103 do you mind no sure we're g go ahead and wrap up because

52:07

we're past time thank again to thank you so much and um we'll let you ask your

52:13

question individually after thank you so much Dr npew

okay so for those of you who saw my original Talk title don't be disappointed um we will be covering

0:11

those topics um but as I got to putting together the slides and really thinking about what I wanted to say to you today

0:18

I thought this was a more fitting title what about Justice um so before I delve

0:24

into kind of some of the content that I want to talk about today I'd like to give you a little bit background of how

0:31

I got interested in this topic and how I came to be someone who studies Justice and health and

0:39

Equity maybe I want to do that I can get my slides to move

0:47

forward let's try that [Music]

1:04

all right now my slides are moving forward now um so I uh have a screenshot

1:11

here um of a very young picture of me um from

1:16

2010 um that top picture is me and my happy bright and unjaded face as a fresh

1:23

graduate getting my match letter to man's greatest hospital um and that

1:29

picture below um is a picture of my head shot again bright naive happy excited ready to go

1:36

into the world um and so as a medical student at Case Western Cleveland Clinic

1:42

learner College of Medicine um my third year I was pretty sure that I wanted to do GI and hepatology and so I was doing

1:49

a rotation and one of the residents said you know one of your patients is going

1:54

to be presented today in liver transplant committee meeting why don't you go to the committee meeting and I

2:00

said okay I said I think he's just trying to get rid of me but it may be interesting okay so I went I sat in the

2:06

back and I came in with this kind of idea of what I expected to happen I

2:11

expected like a big screen to come down and for like all the names to go up on the board and for everybody's clinical

2:18

information to come up and there to be this rigorous discussion about how we can get people to

2:24

transplant and that wasn't what it was um my expectations did did not get met

2:31

um and I can say since that time I have been to many transplant committee me at different centers and there was nothing

2:38

wrong with the transplant committee meeting to happen at Case Western but it was not what I expected it was people

2:44

eating lunch people answering Pages people saying why people weren't eligible without thinking about

2:50

Solutions it was what to me seemed like very casual uh for something so

2:56

substantial um and my patient was not listed he was thought that he did not have enough social support and it was

3:02

given very short discussion um and I was shocked I left that committee meeting

3:07

and I remember uh telling my senior I can't believe this is how committee meetings go was this some type of

3:13

anomaly nobody seemed to be trying to help this patient and he just looked at me and and shook his head um and then I

3:20

had that same conversation with family and friends afterwards and everybody nobody was quite sure why I was so

3:25

bothered but I was very bothered by the whole thing and so I said well I wanna I

3:30

want to be able to talk about this and use some terms and talk about these things that I'm feeling and experiencing

3:35

and this fairness that I feel like is not there in some kind of educated way and so I started Googling um liver

3:43

transplant and fairness and I I came ac across some things about art kathan and

3:48

other folks and I said um maybe if I take a bioethics class I'll be able to

3:53

kind of Express what I'm feeling and talk about it um in a more meaningful way so I took a bio ethics class and a

4:00

bioethics class turned into a bioethics masters um and that's how I landed in

4:06

this space um really wanting to be able to express what I was seeing the

4:12

problems I was seeing in some type of way that wasn't just emotional it wasn't just this doesn't seem like it's right

4:18

um and that's how I became kind of or got on this path of exploring um Justice

4:24

and social justice from a bioethics framework so I learned learned a lot of

4:30

different ethical constructs in transplantation um as a bioethics

4:35

student um that did arm me with some tools to write a lot of good editorials and so we'll we'll run through some

4:42

ethical constructs um in uh transplant I learned about scarce resource allocation

4:48

right and and this idea that there's not enough um to go around and you've got to

4:53

think about how to distribute them fairly um and effectively um and I actually wrote my kind of Master thesis

5:00

around this concept of scarce resource allocation and kidney uh

5:06

transplantation I learned about distributive justice um this concept that even in the setting of scarce

5:12

resource allocation um you have to still understand how the burdens and the

5:18

benefits in healthcare are allocated and distributed amongst all individuals and

5:23

so that seemed to get at a bit of what I was feeling in that committee meeting that yes there's a scarce resource but

5:29

can we ensure um that some people aren't bearing all of the

5:35

burdens autonomy um of course was something that I learned about um that

5:40

you know people have to make informed decisions about whether or not they want to partake in healthcare even transplant

5:46

it's a life-saving Endeavor but everybody doesn't want to do that and that's okay um and there's going to be some people who need to be able to

5:53

express that kind of autonomy um that they aren't interested in transplant for whatever their reasons may be

6:00

he learned about how to be a benefit right um to patients and really thinking

6:06

about transplant and the people who are going to have the best survival and so that becomes a big topic and a big Focus

6:13

that we'll talk about more in transplant and of course we want to do no harm um we want to pick the people

6:22

who are going to have the best outcomes and then finally um some of the concepts

6:27

that I thought about were moral distress um and so I think sitting in that meeting I felt a bit distressed um some

6:34

discomfort um as a clinician um and feeling like there was some injustice and that there was nothing that I could

6:40

do about it and so I was armed with this framework um and and I've written um

6:45

editorials and I've I've thought about these Concepts and and how they applied to the patient that I saw in medical

6:50

school and many of the patients that I see today but I still have to say that even over a decade later I'm left with

6:59

this question it doesn't burn me in the same way it did as a medical student um but I still feel like of the four major

7:07

ethical principles um in transplant and in health care autonomy beneficence

7:14

Nance and Justice why does Justice see receive the least

7:20

attention why is Justice the stepchild of all of the ethical principles and

7:27

what can we do about that and what would it look like what would

7:33

Healthcare look like what would transplant look like what would the world look like if Justice were treated

7:40

as a equal ethical principle in transplantation and so armed with kind

7:46

of the framework about how to think about these things this is the question that drives me every day this is why I

7:52

get up every morning this is why I do the work that I do this is why I apply for grants in the face of executive

7:58

orders because I want to know what would the world look like if people cared as

8:04

much about justice as they did about autonomy so these are objectives that we

8:11

will cover today we will um examine those four ethical principles and we

8:18

will talk about how they're coded into health care and Transplant um and we'll

8:23

talk about how Justice really is not we will then review some of the disp

8:29

ities in liver transplantation and highlight some key access and outcome issues that I think happen as a result

8:36

of really our lack of focus on Justice and then we'll talk about the

8:42

consequences of a failure to deal with our justice issue and because I think

8:48

that there's this idea that not dealing with Justice and not dealing with health and Equity is somebody else's problem um

8:55

but Injustice has consequences okay um and so we're going to talk about public

9:01

perception in Justice and the consequences in organ donation of our lack of focus about uh justice and

9:09

trust and then we're going to dream and talk about what if we were to

9:15

reimagine a just transplant system if I could have some of the things that I

9:21

would like that I would think would move us away from where we are now what they look like um and so we'll end on a on a

9:27

high note but let's start with talking about some of the uh ethical principles in

9:34

healthcare and Transplant and how they are coded um in a part of our kind of

9:40

framework in a way that I think Justice is not so autonomy is a patient's right to

9:47

make their own medical decisions we all understand it and it is legally

9:52

protected okay um the principle is reinforced through informed consent

9:58

shared decision making um if I leave a endoscopy room and I have forgotten I've

10:06

talked to the patient about the procedure I've explained it but for some reason I didn't get their signature and

10:11

I didn't sign the consent form there's five nurses chasing me down the hallway to make sure that those consent forms

10:18

get signed before I put that scope in the patient okay um and so we have

10:24

processes in place to make sure that patients autonomous is documented um

10:31

there are many of us in ethics who spend our career reading about writing about

10:37

talking about informed consent um if you want to overcome someone's autonomy what

10:43

are the situations where that's possible right um so there is um this is not

10:49

something that's just ethical though right this is legally mandated um and there are many processes in place across

10:55

all of healthcare to ensure that people's um autonomy is not violated um

11:01

and so if you would violate someone's autonomy and you know the accreditation folks come and see that there's consent

11:08

forms that are dated and timed after I did the procedure we get dinged our

11:13

endoscopy Suite gets dinged and if you have too many of those that you don't correct you can lose your privileges and

11:19

if it lands on one physician that they aren't getting you know adequate informed consent you know that could be

11:26

a lawsuit right so these are things that are uh ethical principles that we talk about and we write about and we

11:32

pontificate about but they're also regulated um in our laws in our practices at all layers of healthcare to

11:40

make sure that they're respected and I have to say uh you'll see where I'm going with this Justice

11:46

really not so much right um

11:52

nances uh Do no harm um it is also um a

11:57

core ethical principle right um a core principle in medicine that we learn about in medical school um that we

12:03

should do no harm um and we don't want to hurt patients um but it's not just something that we take in our Oaths and

12:10

that we talk about when we get you know um we walk across the stage um to

12:15

receive our kind of you know cap and gown um there are many safety checks to

12:20

make sure that we do no harm to patients right um and so there's infection control protocols if you're on impatient

12:27

service everybody wants to make sure you a gown did you walk out of the room without washing your hands there are

12:32

people who police to make sure that you are not going to pass C death from Patient to Patient to Patient um this is

12:39

something that um is happening in every hospital across the country um there are medication Safety Systems so that we

12:46

scan medicines and make sure that patients are getting the right doses at the right time there's surgical

12:51

checklist their time outs before I can put an endoscopy scope into a patient we have to do a timeout and confirm that

12:58

this is the right patient getting the right procedure and there are many people to make sure that I don't skip

13:04

past that and how many surgeons and proceduralist like me would skip past

13:09

that if there weren't checks in place right it's like ah I know this is the right patient right but it never happens I have never scoped the patient without

13:15

a timeout because there are processes in place to make sure the doct nephew gets

13:21

this done okay um and so a failure to uphold these things if you've got SE if

13:27

running rampant through your hospital if you've got you know infections you will not be

13:33

reimbursed your hospital just will not be reimbursed um and within transplant

13:39

similarly um you know the Mel score was a system is designed in some ways to

13:44

minimize harm right the meld score for those of you who don't do transplant is a allocation score um it's a score that

13:51

tells us how sick the liver is it helps us decide to decide who moves to the top um of a transplant list um and so

13:58

allocation is design to um to take the sickest people first um and it's upheld

14:04

through laws and policies um to make sure that we're abiding by the Mel score and the Mel score is what we're using to

14:09

alligate uh organs um and so um all of these protocols that are in place um

14:16

safety protocols around medicine around transplant around surgical Protocols are

14:22

all put in place so that we don't harm patients um and it's not just left to I

14:28

hope that Dr nephew doesn't harm patients um this is uh there's lots of

14:36

systems to make sure that I don't do

14:42

that you also have an obligation to not just not harm patients right we have a a

14:48

obligation people don't pay us for us just not to harm them they want us to be a benefit to them right um and so

14:54

benefices says that Healthcare Providers are are supposed to benefit p Pati and really act in their best interest and we

15:01

we take the hypocritic oath and that's a really big part um of why we do what we do but again it's not just an oath okay

15:09

they are evidence-based um protocols that guide everything we do um they guide how we

15:15

treat cancer how we treat infection how we treat preclampsia um and if it's

15:21

discovered that you're not following evident evidence-based protocols you can lose your license right um because not

15:27

only are you not supposed to hurt people you're supposed to be providing care that's in their best interest you're

15:32

supposed to be benefiting them following practice guidelines of the current best data and so we meet in groups to make

15:39

sure that we all are following the same practices that you know everybody in our group is doing pretty much the same

15:46

thing um and so these are important um parts of benefiting patients in

15:51

transplant we do the same thing we have listing criteria um that explicitly kind

15:56

of help us to identify the patients we're going to benefit the most from transplant so these are things again um

16:03

that are regulated codified in medical care to ensure we do the right

16:09

thing what about Justice well I would say there's

16:15

lawlessness Anarchy um it's all over the place right

16:20

um there's uh not a similar understanding uh or codification in

16:27

medicine that this principle is anywhere near as important as autonomy um now

16:33

malus and uh beneficence and so what kind of

16:39

structural implementation do we have of Justice in US Healthcare and Transplant system there's been some some Oaths that

16:46

talk about Justice okay so the Declaration of Geneva um the original

16:51

one in 1948 and the revised one in 2017 is probably the closest kind of code in

16:57

medicine that we has that really gets that Justice um that it says I will not permit considerations of age disease

17:04

disability Creed ethnic origin gender nationality political affiliation race

17:10

sex or social standing or any other factor to intervene between my duty and my patient and so I think that's pretty

17:17

explicit kind of a justice statement the modern hypocracy

17:25

will remember that I remain a member of society with a special obligation to

17:31

allow all my fellow human uh to all my fellow human beings those of sound mind

17:37

and body as well as the infirm maybe that's a justice statement it's not quite as clear um as the Declaration of

17:44

Geneva but maybe that's a Justice um statement um but beyond that um unlike

17:50

the other ethical principles this is rather debated and not embedded it's

17:56

talked about it's discussed it's argu argued it's executive ordered but it is

18:01

not um embedded in our practice um and there really no systemic safeguards to

18:07

really ensure or guarantee that anybody gets Equitable care or Equitable access to

18:12

transplantation and so Justice is this kind of idea if you've ever seen this Giving Tree right that um everybody has

18:20

access to the same apples everybody's got the same tools um and then there's this perfect system where everything is

18:27

equal um but unfortunately that's not the world we live in we live in a world

18:32

um of inequality um where there's unequal access to opportunity um and some people have privilege and some

18:38

people don't and people don't have ladders and everybody's trying to get to the same place um but there's really no

18:43

safeguards to ensure that that can that can happen um and so I hope I've I've

18:50

got you thinking even if I haven't convinced you um that the ethical principles that we all study they mean

18:57

something in healthcare they they're codified they are part of why we do what we do um and they are abided by and irbs

19:06

and everybody make sure that we do a good job um but not so much with Justice um and I think that that's unfortunate

19:11

and I think that's why we are where we are today so we're going to talk a little bit about where we are today um

19:18

with disparities and liver transplantation um because I think this is a result of the lack of um focus um

19:27

code requirement um um in this space and so we're just

19:32

kind of out here willy-nilly and that really doesn't get us anywhere um so therosis um is a pretty

19:40

prevalent condition um it was 0.6 per 100,000 in the 90s now we're at

19:48

132.5 per 100,000 in 2017 and you can just see that this barograph is steadily

19:54

inching up and so while therosis may not be a problem that comes to your mind

19:59

like heart disease or breast cancer but it is on the Rise um in the setting of

20:05

alcohol Ade epidemic and obesity epidemic we expect um that mortality from therosis will continue to rise over

20:12

the next decade and so this has becoming a real serious public health issue it's

20:17

always been a public health issue but it's becoming more to the attention of folks who may have been focused on other comities than

20:25

before this is a a complicated figure if you're not of hepatologist but there's really just one thing I want to point

20:31

out um and that is that if you have decompensated liver disease liver

20:36

disease with complications your fiveyear survival is 85% um or your fiveyear mortality excuse

20:43

me is 85% um so this not only is a condition that is on the rise it is a quite more bit condition um and so um

20:51

and unlike other chronic diseases like kidney transplant where you can go on

20:56

dialysis and live live a fairly decent life perhaps or heart failure where you

21:02

may even be able to get a elad and that can help pump your heart for for several years um in liver transplantation

21:10

there's really no other solution you either get transplanted or you die um there's really no Bridge or temporizing

21:17

measure um and so I think when we think about equity in solid organ transplantation in liver disease is

21:23

particularly important because of that lack of bridging therapy

21:29

we're doing more liver transplants than we've ever done before um here at IU we did I think 212 or so liver transplants

21:36

this year when I started here um eight years ago I think we were doing 120 so

21:41

we are doing more and more liver transplants not just at IU but around the country because of some of the

21:46

advances in technology but as you can see in this figure um that despite the fact that

21:52

we're doing more liver transplants which is in the red look how high the weight list is right so just all these people

21:59

um who are on the weight list um who will not get transplanted and this is just the people on the weight list right

22:05

so we're not even talking about the people who never make it to the weight list because of um barriers and access to care um so the burden of people who

22:12

are dying without transplant is probably a lot higher than what um this figure um can um

22:19

display disparities and access to transplant happen um not just at the weight listing space um they happen

22:26

along the whole care Cascade this this is a figure that I like from n the national um Academy of Science

22:33

engineering and Medicine um this is a report they did on transplantation um and it just takes you through some of

22:39

the steps that people don't think about um as much when they think about solid organ transplantation because a lot of

22:45

the disparities start all the way at the diagnosis and disease management step some people might not have needed a

22:50

transplant if their hepsy had been diagnosed right um and treat it because we can cure heepsy now um so awareness

22:56

and education and all the things that lead up to referral evaluation and then

23:01

weight listing doesn't come till here and so much of the focus around Justice and equity and transplantation um if

23:08

there has been any has been at this step right but there are all of these steps that happen before and as we think about

23:13

preventative care and um chronic disease and organ transplantation there's so many things Upstream that we could do um

23:20

in my mind um to kind of help this process I'm going to share with you a

23:27

few um parities for uh some groups so that you can kind of get a context of or

23:32

idea about where we are um starting off with women um and this figure just describes kind of the steps in the care

23:39

Cascade from pre-evaluation evaluation weight listing and a post liver transplant outcomes um and you can see

23:47

that that print came out a little smaller than I expected but um women um are less likely um to um to move from

23:56

diagnosis to evaluation from liver transplant um a study at the University in Michigan showed that women um were

24:04

less likely to be listed even when they in evaluation often due to active substance use issues than men um at the

24:10

weight listing step women have a 50 to 30% higher weight listing mortality than

24:15

men um and are 20 to 30% less likely to undergo liver transplantation and then

24:21

post- liver transplant women have lower quality of life scores um difficulty with psychological adjustment um

24:27

distress um personal um function and so there disparities for women at every step in a

24:34

care Cascade that could be explored when you think about um how

24:39

long we known about disparities and liver disease um or gender disparities and liver disease the sex inity was

24:46

first described by simply moand at Duke in 2008 and if you were to take how long

24:51

we known about it before we did anything about it I think it's been maybe a year since we made a modification to the meld

24:58

score to correct for um to give women a little bit of extra boost okay that just

25:04

happened but we identified this SP in 2008 uh oh uh

25:10

oh um assuming that we had done something about this many years ago 800 women probably would have um still been

25:18

alive and so doing nothing about these disparities and kind of just sitting on them and hoping that they're going to

25:23

get better on their own without changing metal scores Without Really changing policies um is really um life-altering

25:31

and deadly um for the populations who are at a disadvantage Beyond gender I'll show you

25:37

a little race and sces data right here from IU um we looked at over 3,500

25:43

patients who were referred to IU for liver transplantation evaluation between 2011 and

25:48

2018 um you can see the demographics of the people who are referred um 41%

25:55

Medicaid uh 12.5% rural 39% women so our

26:00

referral um patient population in many ways does mirror the population of

26:06

Indiana except for by race all right so 12% of hooers are black and only 6% of

26:12

those who are referred um were black and understanding that um there's a higher

26:17

burden of liver disease in many racial and ethnic bity groups we probably would expect to see over 12% just like in

26:23

Medicaid 40% of hoers don't have Medicaid I think it's somewhere in a 20 to 30 per range but that population has

26:29

more uh liver disease so as expected you see that they're over represented and so you would expect to see that uh probably

26:36

in Rural and in Black patients when we looked at who was dying

26:41

during eval um for transplantation uh we didn't see race or gender differences

26:47

but we did see that coming from a a neighborhood that experiences poverty um made you 50% more likely um to die

26:54

during transplant evaluation this was when controlling for race gender um individual social economic status

27:00

disease comorbidity liver disease severity and this still stood the test of a robust um

27:07

evaluation um and then on the weight list we saw the weight listing um the neighborhood poverty was also associated

27:13

with weight listing and so when people thinking about what are the solutions how do you

27:19

fix um some of these disparities that I'm talking about one of the thing that comes to your mind is

27:27

um that National policies Medicaid expansion um I think we have a tendency

27:33

to really want to push the buck on Justice to somebody else okay um and so

27:39

um that's how I thought when I first started doing this work I said I want to look at and see you know how to Medicaid

27:45

expansion help these problems because that's the way to fix um Health disparities um and so what we found um

27:52

when we looked at the impact of Medicaid expansion on access to the weight list for transplantation um we can see that

27:59

in the kind of grayish blue bars um that there was some small increase in Hispanic patients um listing um but

28:06

there was not the similar increase in white or black patients and so um while

28:12

policy is important it is necessary um National policies around Insurance are

28:17

not sufficient to deal with the justice issues that we have in

28:23

transplantation some people would say well our Health Care system is just not as as robust well I can tell you they

28:30

have the same problem in Canada okay so this is Canadian data looking at area level income um and as association with

28:38

liver transplant access um this is a populationbased cohort over a 20year period of individuals from Ontario

28:45

Canada um and what they found was that living in a poor neighborhood once again was associated with um um a 50% less

28:54

likelihood almost of being transplanted and this is in a place where they have Universal healthare and so again I'm not

29:01

knocking Universal healthare I don't want to or Medicaid expansion I think that these are very important programs

29:07

and that they are necessary for us to do the additional work we need to do to codify justice but they aren't

29:13

sufficient and so this idea that if they just do more in Washington this problem would go away is likely not true um

29:20

there's more that's going to have to be done than just giving people Universal healthare um to deal with the inequities

29:26

that we have here um and trans in healthare in

29:31

general so what does the public think about our Justice problem maybe it's just me right maybe I'm the only person

29:39

who has a problem with Justice maybe it's just me the seed was planted as a medical student and nobody else is

29:45

bothered by this that's not true okay um so the public doesn't trust us either

29:52

okay uh so this is data from the 2019 National survey of organ donation attitudes and practice practices it's

29:58

over 10,000 participants in this survey um they over sample and make sure that they've got demographic representation

30:06

of Asian Americans Native Americans black Americans it's a very well done study um and so if you look um at the

30:14

number of folks who believe our donation system is fair it's about

30:20

66% maybe we think that's a win but if my you know I don't know that's like my

30:25

my son coming home and telling me I got a 66 % it's like 40% of people don't

30:31

think our distribution or donation system is fair I would say we have some work to do there um if you ask people do

30:38

you have an equal chance of getting an organ if you're rich or poor about 52% of people believe that to be true so 50%

30:45

of people don't believe you have an equal chance of getting an organ if you're poor okay and then more striking

30:51

and maybe hard to read um is that uh 48% of people now believe that minorities

30:57

are less likely to receive an organ transplantation and you can see the increase they do this study every five

31:03

years or so so you can see that went from 29 to 30 to 48% we aren't just

31:09

asking minorities this question they ask everybody this question everybody knows the system isn't right right so people

31:15

recognize and perceive the Injustice we're not like hiding back here in healthcare um they recognize that the

31:22

system isn't quite right why is trust important in Oregan

31:29

allocation this is arap quote I don't believe everything he says but I think this is a good one um the values of

31:35

altruism and autonomy the foundations of organ procurement rest on the presumption that organs which are given

31:41

freely voluntarily and altruistically will distributed in a fair and impartial

31:46

manner to those in need any policies practices or activities that suggest otherwise and Peril the entire

31:53

Enterprise of voluntary and alteristic organ donation and when the public

31:59

declines uh trust declin so does Oregon donation rates and that's been shown in

32:05

several studies and so the Public's perception around organ

32:12

transplantation and their and perception of inequity and lack of fairness it just

32:18

keeps that organ donation number low you see how many people are on the weight list right if we want people to really

32:23

buy into the system then we've got to get over people's um perceived um I

32:29

don't even want to call it perceived their recognition of the injustices in the

32:35

system and so this is something that I in my mind I just describe as kind of a

32:41

vicious cycle um this Justice trust cycle right um so when Justice is embedded into policies and practices it

32:48

builds trust people trust the system they perceive it to be fair they think

32:54

transplant is Equitable and all is well so when Justice strengthens trust trust

33:01

increases participation and organ donation and then precip uh participation reinforces Justice because

33:08

if everybody's involved in the system everybody's making recommendations about how to move things forward you got community engagement and you just go

33:15

around this nice pretty kind of Justice trust um cycle if things are going right

33:21

when things are not going right the cycle gets broken right um so breaking a cycle through unequitable policies and

33:28

uh practices leads to distrust disengagement people aren't a part of

33:33

the process they don't want to donate they aren't a part of making rules about the uh the system because they don't

33:38

feel like they're they're even consider um and then you get whing disparities um so I don't think we're in the left box

33:46

unfortunately when it comes to transplant I think that this cycle um is becoming broken and it's evidence as 49%

33:54

of Americans recognizing that that really there's some infer unfairness is happening we looked at this um question

34:03

of whether or not um people's perceived inequality when infect uh their

34:09

likelihood to be a living donor um and so we use some of this organ attitude data um and this is a multivariable

34:16

analysis um and you can kind of see here that even when controlling for race

34:23

income whether or not you worked what region of the country you lived in whether you were rural how much

34:29

knowledge you had about transplant um your religion um if you perceived the system to be unfair you

34:36

were less likely to donate um and and so you know these things have consequences for all of us

34:43

um and so when people are less likely to donate more people die we aren't the only people that show this this is a

34:50

medical distrust and it's association with the intention to donate this was a study that was done in all

34:55

African-Americans 585 African American um survey um participants um and you can

35:02

see that people's verbal intention to donate that kind of first stage of change um even when controlling for

35:09

other factors um was associated with medical distrust um and so in a cohort

35:15

of 10,000 kind of diverse subjects in our study um even looking particularly at minoritized groups this idea of not

35:23

trusting a system to be fair and just has consequences conse quences um that I

35:29

think really affect all of us am I doing on

35:37

time all right all right okay

35:42

so I have time to drain so what if I was gonna reimagine a

35:48

just transplant system um yes yes if there are questions at the

35:55

end if you want to put them in the chat or um just unmute yourself that's fine too um so if I was going to reimagine a

36:02

just transplant system I'm not going to go way out there okay with things that I

36:07

don't think are possible so this is my pragmatic wish list okay um the first

36:12

and most important thing in my mind is National transplant Equity metrics and I

36:18

hope that the whole talk has prepared you for this bullet point and you believe that this is the way to go I

36:25

hope I've convinced you that when we codify um principles ethical principles

36:31

they become true they become practiced they become adhere to um and I think

36:37

that like every other ethical principle this is the way to go um with Justice

36:42

and Equity I think that this will drive many other things um including some of

36:49

the other things I think that we practically need to help people through the system we need an acknowledgement of

36:54

social needs and health literacy we need access to care Pathways but I don't

36:59

think those things are just going to happen I think that those things will happen if we make them

37:05

happen nobody likes the word regulation um but I do believe that

37:11

thoughtful regulation um as we've talked about with an autonomy and beneficence

37:17

um can foster accountability um nurses to check with me to make sure I'm doing the right

37:22

thing resource allocation we've got whole quality committees to try to make sure we don't have too much CI um and

37:29

data driven approaches poorly designed regulation though can incentivize gameing the

37:35

system um and can really harm centers that don't have the

37:40

resources to do the things that going to be needed to meet those Equity metrics

37:46

and so it's really important that if we were to come up with national Equity metrics that people who do this for a

37:53

living who understand Equity who understand transplant are in the room to consider these things um to come up with

37:59

something that's going to be uh useful there are many examples um outside of

38:05

the ones I've given um for regulation driving um Innovation and Medicine um

38:11

and so H

38:19

oh um Hospital readmission programs uh meaningful use programs qual metrics and

38:26

dialysis centers these are all kind of regulations um that have driven um

38:33

change and and improved outcomes especially in dialysis um for patients

38:38

and so there is a um a framework for us

38:43

coming up with regulations and them driving Innovation and accountability and improving the care um of

38:49

patients um and their families what would be an example what

38:55

does that look like one example might be um dealing with catchment area mismatch

39:02

what does that mean does the transplant centers weightless reflect the demographics of the population it serves

39:08

in any way in a little bit of way you would think that would be something that we would look at but it's

39:14

not you know we don't Define service areas in any way um we've done no

39:21

there's no standard needs assessment if you work at a Federate qualified Health Center if you've ever worked at one

39:27

there's a requirement that you define your service area that you do a need assessment every three to five years for

39:33

what the needs are and that you act on the needs in the community it's reasonable if they're going to give you money it's not a reasonable um

39:40

unreasonable ask we don't do that in transplant and I think that we should um and I think that we would not ask a lot

39:47

right you do A needs assessment you outline a fiveyear plan you don't close the gap all together maybe you close it

39:53

by 10% and we incentivize it in some way transplant we don't tend to iniz we tend to

39:59

penalize um if you don't have 92% post transplant outcomes or better um then

40:05

you're no longer a blue clear Shield um Center of Distinction and and things like that and so everybody's pushing for

40:12

that good post transplant outcome and we design all these systems to make sure everybody does well in the first year it's driven a lot of innovation um but

40:20

it's a penalization system I think we have to think of ways to kind of incentivize things and and a do some um

40:25

positive parenting I think that um the first bullet point

40:34

was kind of um a national metric the second bullet point um we're kind of

40:39

coming up with social needs screening systems and access to Care Systems um this is something that we're working on

40:46

our pilot study is funded um by the ND it's a r21 um but my thought is that why

40:52

is this like why do I have to have a grant to do this like why is this not just what we do right so we spent time um engaging with

41:01

Community um gastroenterologists talking to them about what they thought they needed to get people to our transplant

41:08

center um designing a referral toolkit um and putting together a set of systems

41:15

that would help providers patients um um and GI practices and we're rolling it

41:22

out um at eight practices across Indiana but when the money's gone it's gone

41:28

right so then I have to try to apply for another Grant to do what seems like to me good

41:34

care um I'm going to skip this um and end on um the African-American transpl

41:40

Access program at Northwestern I think this is another example of a grassroot eort to improve access to transplant

41:47

this they're constantly looking for funding um it's a program that deals with distrust cultural comp competency

41:53

psychological support and health literacy is run by da Simpson she's a black um transplant surgeon at

42:00

Northwestern since she started a program in 2019 um they increased referrals um they

42:06

increase evaluations and they increase listing um of black patients in the Chicago area um and so that's not a long

42:13

time to have an impact um and she's doing this with one nurse coordinator like one social worker and herself um

42:20

and so um transplants make Hospital Systems a lot of money um and so if you

42:26

can do more transplants she's probably paid for her program um but she's

42:31

constantly looking for funding right so in conclusion um I'll leave you with these

42:38

few points um that um these are ethical principles are coded into practiceing

42:44

health care and Transplant why not Justice gender race and SCS disparities

42:50

are prevalent at every step in the care journey and insurance is really necessary uh but probably not sufficient

42:56

to fix the problem we're going to need more um than that public perception is

43:02

important um it drives a cycle of disengagement that impacts marginalized

43:08

folks but also majority folks okay so this is this a problem that it hurts

43:14

everyone and I imagine a system with smart regulation that really would

43:20

facilitate uh Community engage Solutions um and so I hope that you know one day

43:26

I'll get some to buy into that and we all aren't looking for funding for programs that really should be codified

43:33

into um our routine transplant care um I'd like to thank all the

43:39

funders and my research team and I'll pause here for any

43:51

questions you can take um questions from here in the room and then there should be Q&A questions coming to you I can't

43:57

access it myself I'm sorry otherwise I would read them to you Nick will take over your computer

44:02

and look at the Q&A online and we can see if anybody here in the room has a

44:07

question yes so there's one question in the chat let's see in residency we heard

44:14

frequently that wealthy non US citizens were able to sometimes game the organ

44:19

system by paying out a pocket for an organ transplant and bypassing the usual organ transplant protocols this in

44:25

contrast to hearing over over and over again and undocumented non- US citizens are not eligible for transplant can you

44:31

clarify if this is true or not and comment on your thoughts regarding transplant tourism oh that's a whole

44:40

talk um but um there are a few things I can kind of clarify um transplant of

44:47

non- US citizens is transplant center in state specific um there is no National policy

44:54

on transplant of non- US citizens many Centers do not do it because of the cost

44:59

because in most in many states you cannot get Medicaid as a non- US citizen

45:05

um and if you can't get Medicaid then you can't pay for transplant you can't get your post transplant meds that's been our party line here at IU is that

45:12

undocumented immigrants cannot get insurance and then therefore cannot pay for transplant so we have not been a

45:18

center who does that but there are centers in New York and in California that have funds set aside to transplant

45:26

undocumented IMM in certain cases um how do they decide it's often young moms who

45:32

have acute liver failure of pregnancy and and in cases that they can kind of get philanthropy to kind of help with um

45:39

with that but that's not something we've done at IU so a state and Transplant Center specific there's no National policy that says you can't do it um I

45:46

actually have a student who's working on a survey to get transplant center attitudes around that um because she's

45:52

on the global Health Track and what really interested in that so she's pulling together survey so stay tuned for what folks think about that in terms

45:59

of gaming the organ donation system you can't game it per se but you can list at

46:06

multiple centers if you have money um and so you can go to multiple centers in

46:11

different regions which may have different weight times and be on the list at multiple centers around the

46:17

country and some people can't afford to do that and then centers have different weight times depending on where they are

46:23

there's been a lot of policy to try to even out weight times AC across the country that haven't quite been

46:29

effective so there still are sometimes places where people used to come to Indiana for that our weight times used

46:34

to be short before some policy changes um or what you know this would be a place you want to list Indiana

46:41

Florida um not as much anymore but if you do have money you can list at

46:46

multiple

46:51

centers is this oh it is working great yeah

46:57

thanks Dr nephew for the talk extremely well organized follow like flowed very

47:02

logically appreciate it um I agree with this observation that we've done a much

47:08

better job with three of the four sort of bioethical principles and part of my

47:15

reflection on that is like as clinicians we think at an individual

47:21

level like the patient in front of us or maybe the patient the next day like much easier and so this principles are sort

47:27

of like in practice you can sort of see them and understand them more the Justice one I think my what I think is

47:35

that um it's harder right to sort of grasp as a as a clinician and not saying

47:41

that we shouldn't do it I think I'm just trying to explain maybe why this is and then I say that and think about your

47:47

final proposal as well and I'm they seem to be like large policy levers policy

47:55

solutions that you're advocating for and I wondered like to

48:00

whom would that responsibility fall on do you think I mean you're identifying the Grassroots efforts you know which

48:06

which are are sort of great but like they they found a champion right like someone to really do this right is it

48:12

the transplant centers is it the larger sort of national you know organ allocation um bodies that that sort of

48:20

do this who does this I think it's the larger organ allocation body so the United Network of organ sharing sets our

48:27

metrics for post transplant survival for weight list um outcomes the metrics that

48:33

we are judged on come from them and if you don't do well they will shut your transplant center down if you know if

48:40

you have too many people who are dying after transplant which means that your listing criteria are not right um and so

48:46

we can all well I can think about programs that this has happened to um and so I think just like they

48:52

regulate our post transplant outcomes and some our other outcomes they need to think about how to set some metrics for

49:02

this um I think that if they set the metrics transplant centers will figure

49:08

it out yeah um I don't think that they should tell us how to fix the problem I think that they should acknowledge there

49:14

is a problem worth fixing for all of us tell us you know by what margin we need

49:19

to fix it and then every transplant center is going to have different needs what they do in Chicago

49:26

um for black patients because of the patient population they have there may not work in Houston you know they're

49:33

going to be um but you will figure it out and if you go across the country all of us have different ways of managing

49:40

patients in that first year post transplant we all get to that 92% goal but everybody's kind of got a different

49:47

formula for getting there there's some principles that we share and then some things that are unique to us being

49:52

everybody being three hours away for us in Indiana because we're the only transplant center in the state that they don't have to deal with in New York or

49:58

Boston where everybody's there's so many transplant centers right so we have to think about our one-ear survival and our patient population a bit differently so

50:05

I do think I do think Innovation will happen at the transplant center level but I don't think there's impetus to

50:10

spend the money to do it and to innovate and think creatively without some regulation that comes down from our

50:16

governor bodies

50:24

yeah there's one more Yep in my work with transplant teams I have noticed a unique dual obligation that many

50:30

clinicians do not feel or feel much l strongly um they seem to feel that traditional obligation to acting in best

50:36

interest of patients but also feel a strong obligation to acting as stewards of scarce resource um can you speak um

50:46

about your experience with this tension yeah um so you know we as

50:53

transplant um providers we are dealing with a scarce resource and you want to

50:58

give a scarce resource to the people who you think are going to do best with it survive the most with it um and that may

51:04

not be someone who's got poor social support or who are struggling in some of these areas um post transplant in your

51:11

mind um how I deal with it um is I let the transplant team deal with that when

51:17

I'm talking about my individual patient I am advocating for that patient within

51:22

reason okay like I'm not saying that I'm like transplanting like just any body but within reason my commitment as that

51:31

patient's doctor is to that patient not to the system and everybody else is on

51:36

the committee can think about the system um but when I'm presenting my patient I'm presenting my patient to get a

51:43

transplant um and so I try not to think about who's not getting a transplant

51:48

because I feel like that's not my job for an individual patient and then I let all my colleagues think about that it's

51:56

time for one more question we're a little bit over is there another one online no I don't think so to our final

52:02

question maybe maybe we should wrap up because it's 103 do you mind no sure we're g go ahead and wrap up because

52:07

we're past time thank again to thank you so much and um we'll let you ask your

52:13

question individually after thank you so much Dr. Nephew