



**Brigham and Women's Hospital**

Founding Member, Mass General Brigham

## **Ethics in Nephrology: from the bedside and beyond**

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- University of the Witwatersrand, South Africa
- Medicine Residency @ University of Miami
- Nephrology Fellowship @BWH and MGH
- MSc Public Health in Developing countries @ LSHTM
- PhD Biomedical Ethics @ U of Zurich
- Affiliate Lecturer of Medicine@ HMS
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- Deputy chair Advocacy Working Group @ ISN
- Clinical focus: CKD, Dialysis, AKI
- Research focus: Priority setting, Equity in access to care in resource limited settings



# Disclosures

- Royalties as co-editor of textbook “Brenner and Rector’s The Kidney”, Elsevier
- Honoraria: Editor for special issue Seminars in Nephrology, NephSAP; PhD examiner, U of Sydney; grant reviewer - DKF
- Grant funding from the Swiss Kindey Foundation
- Travel to meetings reimbursed by KDIGO, ERA, ISN



# Key learning objectives

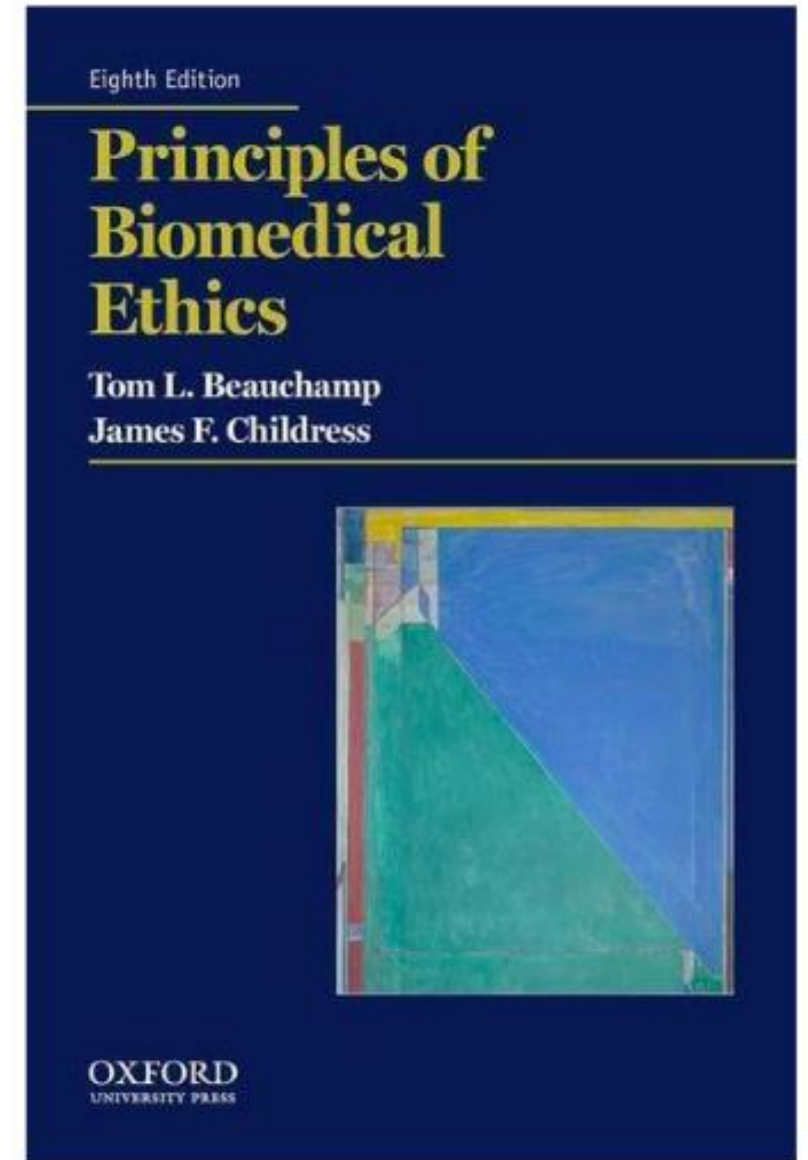
- Understand and apply principles of biomedical ethics in nephrology
- Consider broader implications of ethics in nephrology, using the example of dialysis
  - Community perspective
  - Global health perspective
  - Moral distress



# 4 Principles of Clinical Ethics

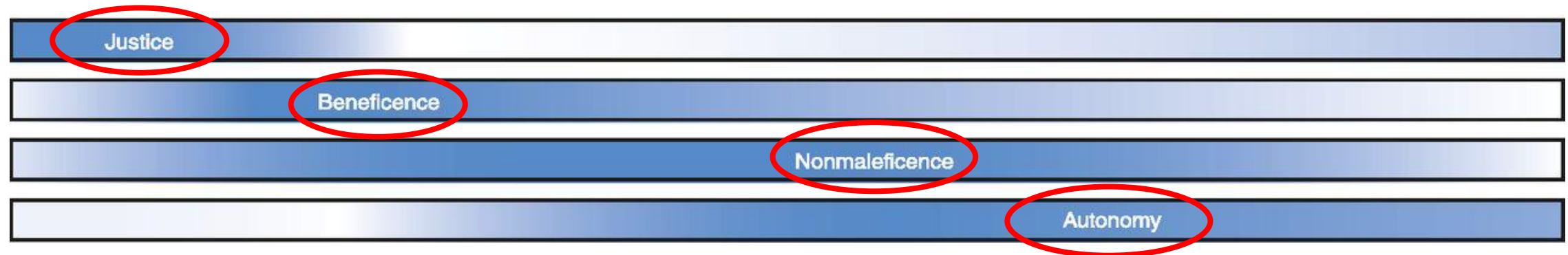
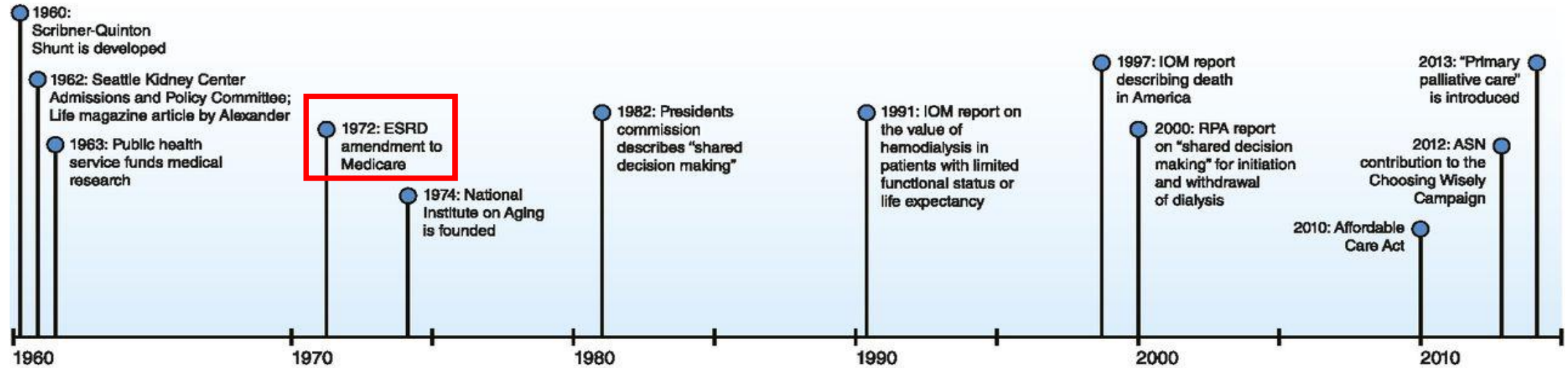
- Respect for Autonomy
- Beneficence – do good
- Non-maleficence – do no harm
- Justice

Beauchamp and Childress, principles of Biomedical Ethics, 8<sup>th</sup> Ed 2019, Oxford Univ, Press



# ESKD in the USA in 1960s

## – the birth of biomedical ethics



# Traditional issues and Foundational Principles and Values in Bioethics and Public Health Ethics

	TRADITIONAL ISSUES	FOUNDATIONAL PRINCIPLES AND VALUES
<b>Bioethics</b>	<ul style="list-style-type: none"> <li>• Informed consent and patient agency</li> <li>• Reproductive and end-of-life decision-making</li> <li>• Use of emerging technologies/ bedside rationing</li> <li>• Clinical research ethics</li> <li>• Confidentiality</li> </ul>	<b>Autonomy</b>  Beneficence Non-maleficence Justice/fairness Utility Caring
<b>Public Health Ethics</b>	<ul style="list-style-type: none"> <li>• Vulnerable populations/uninsured</li> <li>• Infectious disease control</li> <li>• Social determinants of health</li> <li>• Cost-effective decision-making</li> <li>• Emergency preparedness</li> </ul>	<b>Population-level utility</b> <b>Evidence</b> <b>Justice/fairness</b> <b>Accountability</b> <b>Costs/efficiencies</b> <b>Political feasibility</b>  Beneficence Non-maleficence Autonomy

# Conflicts between principles of biomedical ethics

<b>Benefit</b>	<b>vs.</b>	<b>Risk</b>	Rituximab for glomerulonephritis
<b>Autonomy</b>		<b>Benefits/Risks</b>	Any test/treatment e.g. genetic testing
<b>Autonomy</b>		<b>Solidarity</b>	Mask use during COVID
<b>Confidentiality</b>		<b>Disclosure</b>	Screening of family members for PKD
<b>Autonomy</b>		<b>Stewardship</b>	“rationing” of access





# Relevant concepts in clinical medicine that impact ethical/moral practice

- Social determinants of health
  - Poverty, catastrophic expenditure
  - Geography
  - Gender
  - Education
- Vulnerability
- Incentives (research, clinical)
- Conflicts of interest



# AUTONOMY



# Respect for Autonomy



- Autonomy
  - Intentionality
    - May need to decide between conflicting options
  - Understanding
    - May be limited by age, illness etc.
  - No controlling influences
- Requires respectful treatment

# Autonomy

- first-person autonomy, which is the individual's duty to make good decisions for themselves
- second-person autonomy, which is the presumption that others act in their best interest



# **BENEFIT vs. HARM**

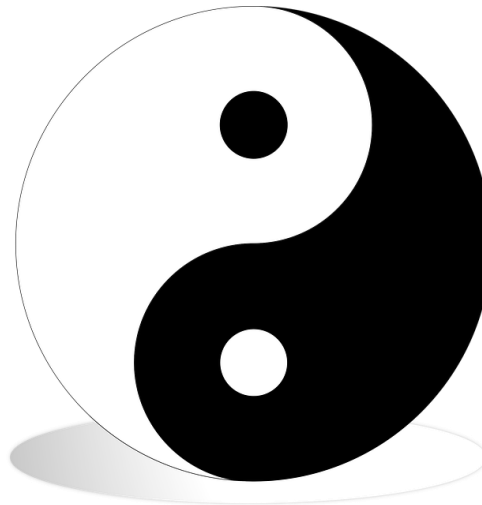


# Beneficence

- Prevent harm
- Remove harm
- Do or promote good

# Non-maleficence

- Do not cause harm



# Examples of ethical challenges between beneficence vs. nonmaleficence

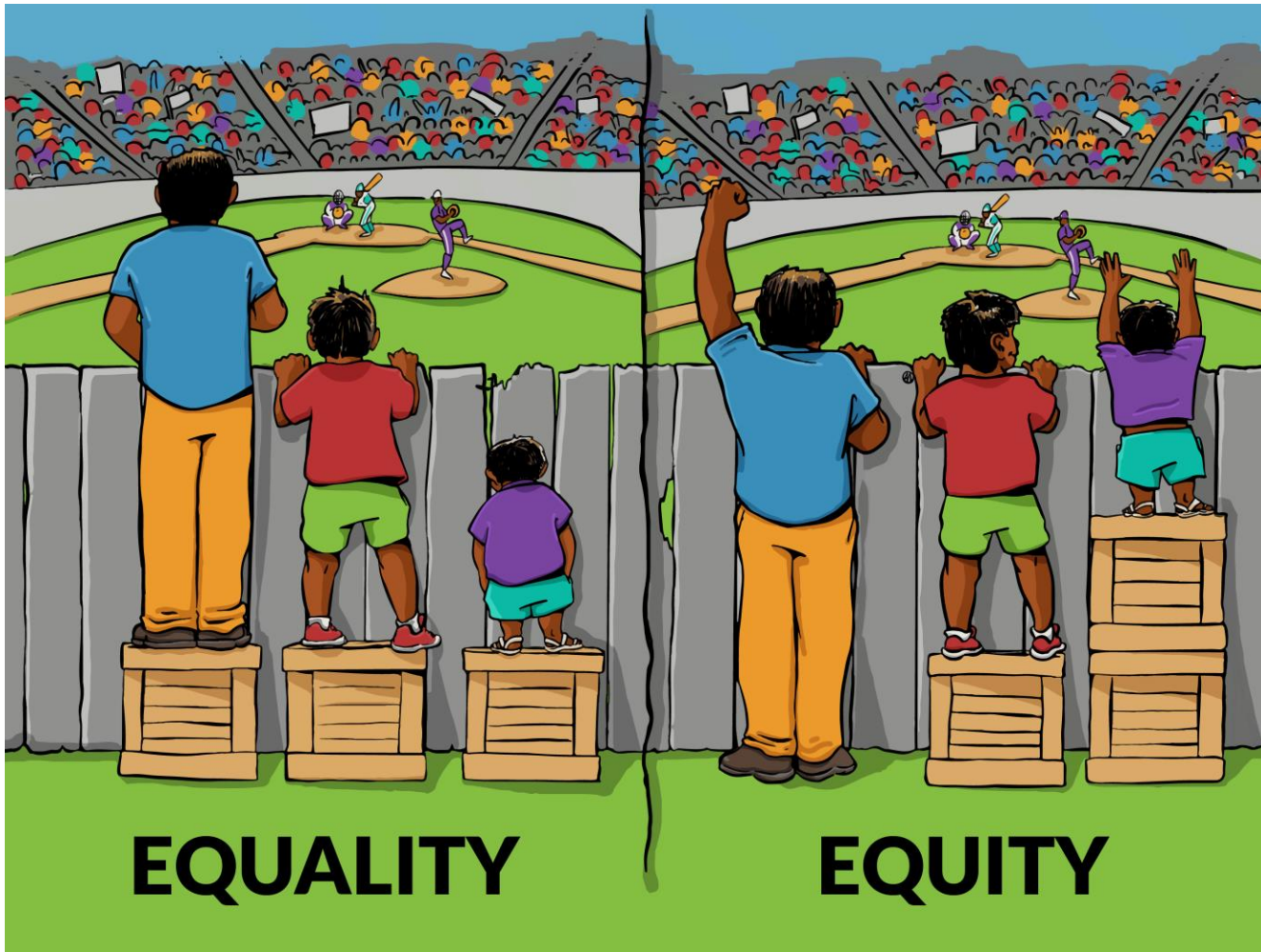
- Treatment burden - benefit
- Quality of life judgment?
  - Autonomy
- Withhold vs. withdraw ?
- Futile care?
- Duty of rescue?
- Access to research medication
- Cost, benefit, risk?

# JUSTICE





# Justice



## Fairness

### Equity:

- “Equals must be treated equally”
- “Unequals must be treated unequally”

Image from “Interaction Institute for Social Change | Artist: Angus Maguire.” [interactioninstitute.org](http://interactioninstitute.org) and [madewithangus.com](http://madewithangus.com).



# Examples of ethics in practice: dialysis



# Individual challenges



# 7 elements of informed consent

## **Threshold elements (preconditions)**

Decision-making capacity

Voluntariness

## **Information elements**

Disclosure of material information

Recommendation (of a plan)

Understanding the information and recommendation

## **Consent elements**

Decision in favor of a plan

Authorization of a plan

# Is the patient able to make a decision (competent)?

1. Can express/communicate a choice or preference
2. Can understand own situation and consequences
3. Can understand relevant information
4. Can give a reason
5. Can give a rational reason
6. Can give risk/benefit reasons
7. Can reach a reasonable decision
8. *Apply similarly to surrogate decision-makers*



# Dilemmas regarding dialysis initiation at extremes of age...

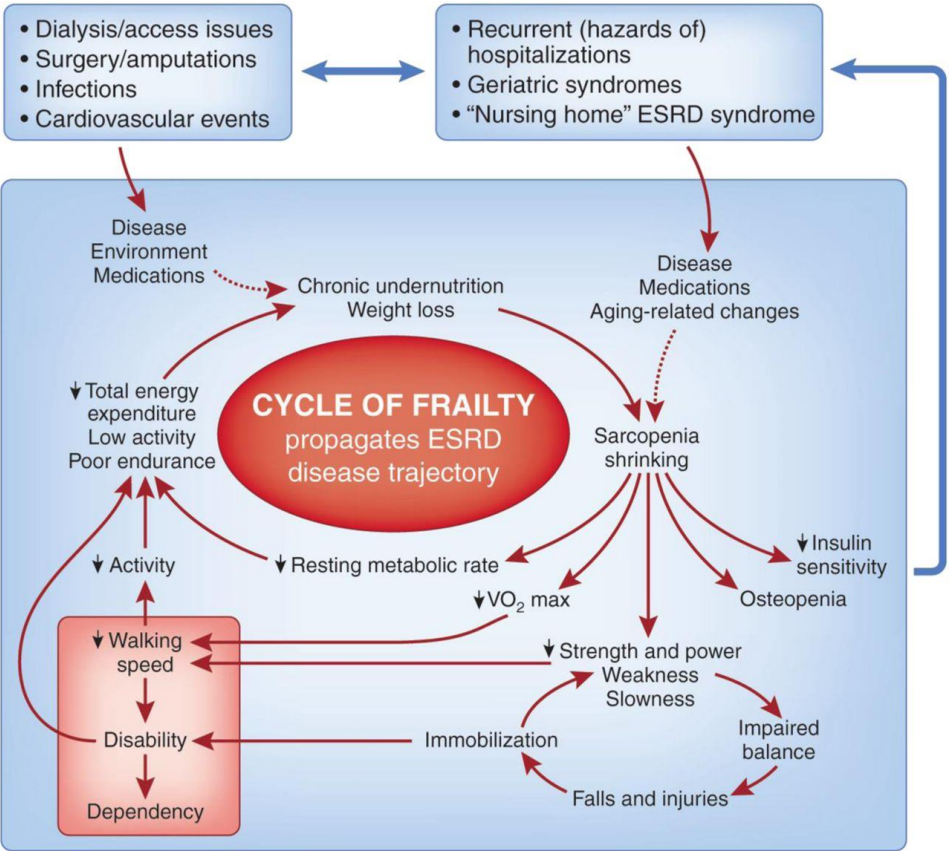


Table 2. Pediatric nephrologists’ beliefs about dialysis for infants

Series	Geary (15)	Teh <i>et al.</i> (14)
No. of responders (response rate)	361 (43%)	180 (21%)
Offer RRT to any infant <1 mo	93%	98%
Offer RRT to all infants <1 mo	41%	30%
Believe it is never acceptable for parents to refuse RRT for infants <1 mo	19%	27%
Believe it is usually acceptable for parents to refuse RRT for infants <1 mo	50%	NA

NA, not applicable.



# Shared decision-making

**PERSPECTIVE**[www.jasn.org](http://www.jasn.org)

## Enabling Patient Choice: The “Deciding Not to Decide” Option for Older Adults Facing Dialysis Decisions

Fahad Saeed <sup>1</sup>, Alvin H. Moss <sup>2</sup>, Paul R. Duberstein,<sup>3</sup> and Kevin A. Fiscella <sup>4</sup>

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<sup>3</sup>Department of Health Behavior, Society, and Policy, Rutgers School of Public Health, Piscataway, New Jersey

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JASN 33: ●●●–●●●, 2022. doi: <https://doi.org/10.1681/ASN.2021081143>



Piccoli et al. *BMC Medical Ethics* (2017) 18:61  
DOI 10.1186/s12910-017-0219-4

BMC Medical Ethics

CASE REPORT

Open Access

# The strange case of Mr. H. Starting dialysis at 90 years of age: clinical choices impact on ethical decisions



Giorgina Barbara Piccoli<sup>1,2\*</sup>, Andreea Corina Sofronie<sup>2</sup> and Jean-Philippe Coindre<sup>2</sup>



BARRIERS TO OPTIMAL DIALYSIS

Guest Editor: Mark Williams

—Seminars in Dialysis

WILEY

# Dialysis adequacy reconsidered: The person comes first

Ann M. O'Hare  





OPEN ACCESS

# Is withdrawing treatment really more problematic than withholding treatment?

James Cameron,<sup>1,2</sup> Julian Savulescu,<sup>1,2,3</sup> Dominic Wilkinson <sup>2,3,4</sup>

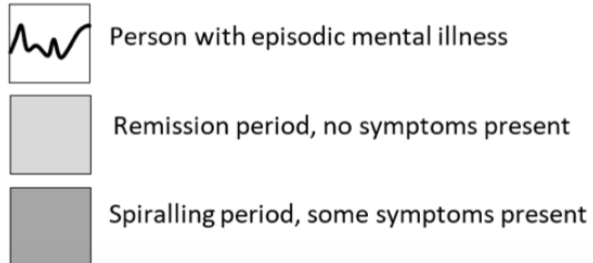
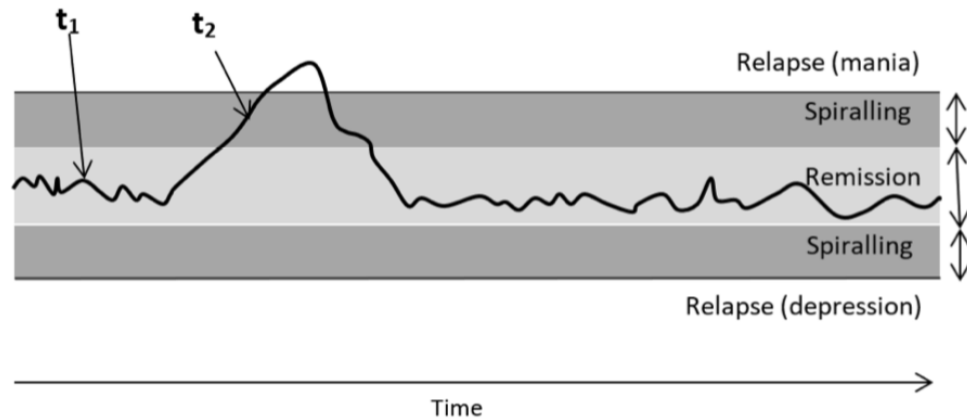
- Same decision not to provide treatment
- Implications of withdrawing?
- Implications of not-withdrawing?

# Challenge of the disruptive/difficult patient?

Ethical Duty	Nonadherence Considerations
<b>Respect for autonomy:</b> to respect the right of a competent patient to make informed, voluntary decisions about their own care in accordance with their values and preferences	Has the patient expressed a <u>desire for dialysis</u> ? Has the patient provided reasons for their nonadherence? Does the patient have the capacity to make decisions about their care?
<b>Nonmaleficence:</b> to do no harm to a patient This includes not providing care that the nephrologist does not consider appropriate	Is the nature of the patient's nonadherence <u>harmful to them</u> ? Are <u>other patients potentially harmed</u> by the patient's nonadherence?
<b>Beneficence:</b> to do what is beneficial for the patient, with a focus on maximizing benefits whilst minimizing harms	Are there <u>actions that can be taken</u> to address the patient's nonadherence that would be in the patient's interests?
<b>Respect for dignity:</b> to recognize when the provision of certain care (particularly when not delivered in private) might be undignified for the patient, and to avoid this where reasonably possible	Do the measures taken to allow dialysis delivery (i.e., restraint) undermine the <u>patient's dignity</u> ? Do other patients witness these measures?
<b><u>Proportionality</u>:</b> to provide the care that achieves care goals with the least infringement/in the least restrictive way	Are there <u>alternative methods</u> of delivering dialysis that are less invasive? Might the patient's care goals be met by nondialytic care?
<b>(Distributive) justice:</b> to act impartially and avoid inequalities where possible, ensuring that resources are allocated justifiably	Are significant <u>resources needed</u> to overcome the patient's nonadherence? Will <u>other patients have to forego care</u> if means of overcoming the patient's nonadherence are pursued?



# Challenge of the disruptive/difficult patient?



Ulysses contract?





## Issues related to unvaccinated patients on haemodialysis



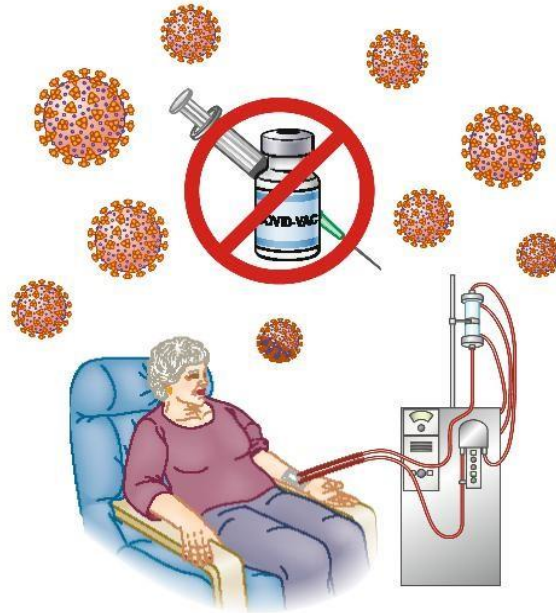
Bed occupancy  
Hospital workload



↑ Risk of SARS-CoV-2  
transmission to HD patients



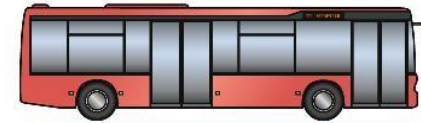
↑ Risk of SARS-CoV-2  
transmission to  
other patients



↑ Risk of severe  
COVID-19



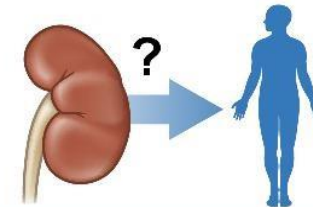
↑ Risk of SARS-CoV-2  
transmission to  
healthcare workers



↑ Risk of SARS-CoV-2  
spreading on public  
transportation



↑ Risk of SARS-CoV-2  
transmission to relatives

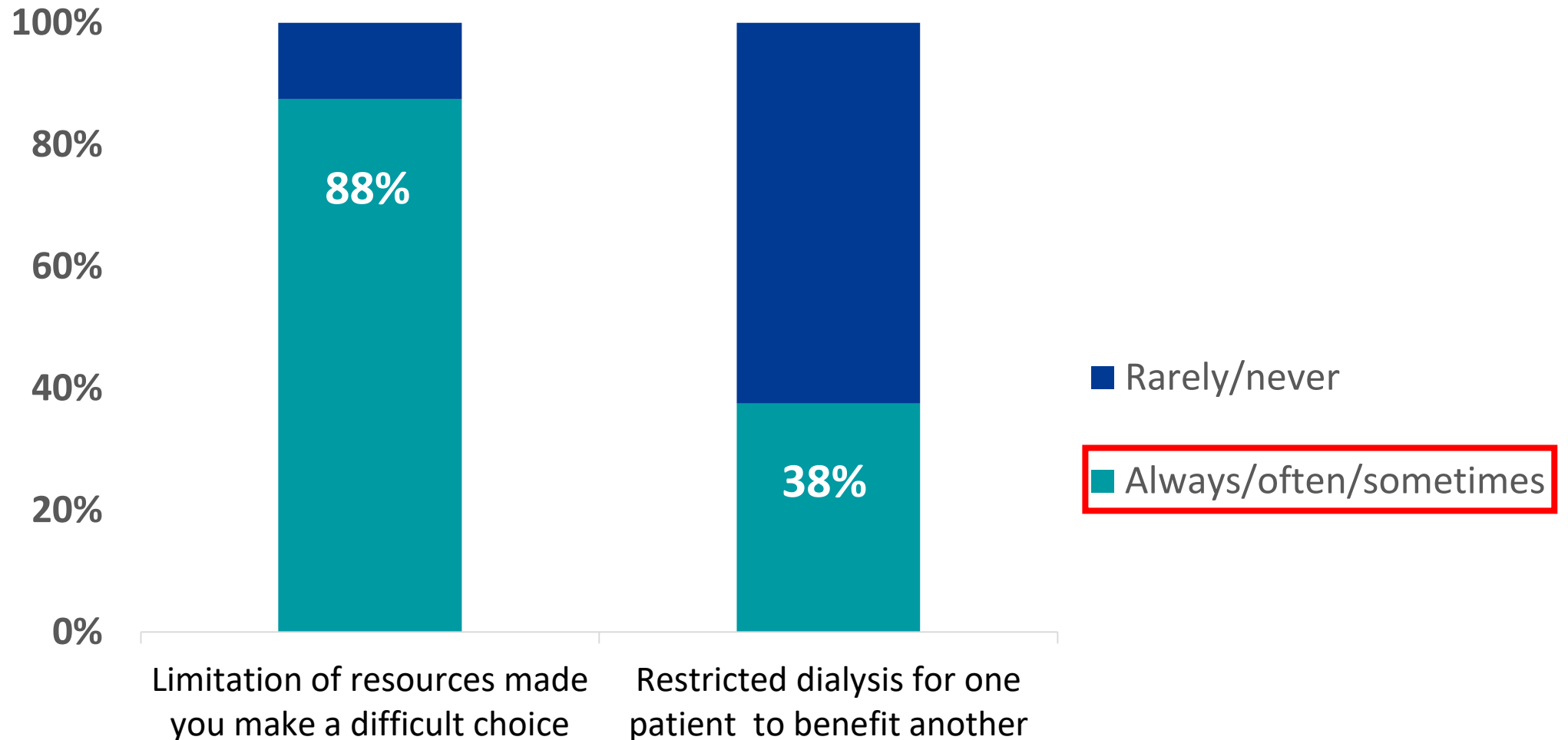


Eligibility for  
kidney transplantation

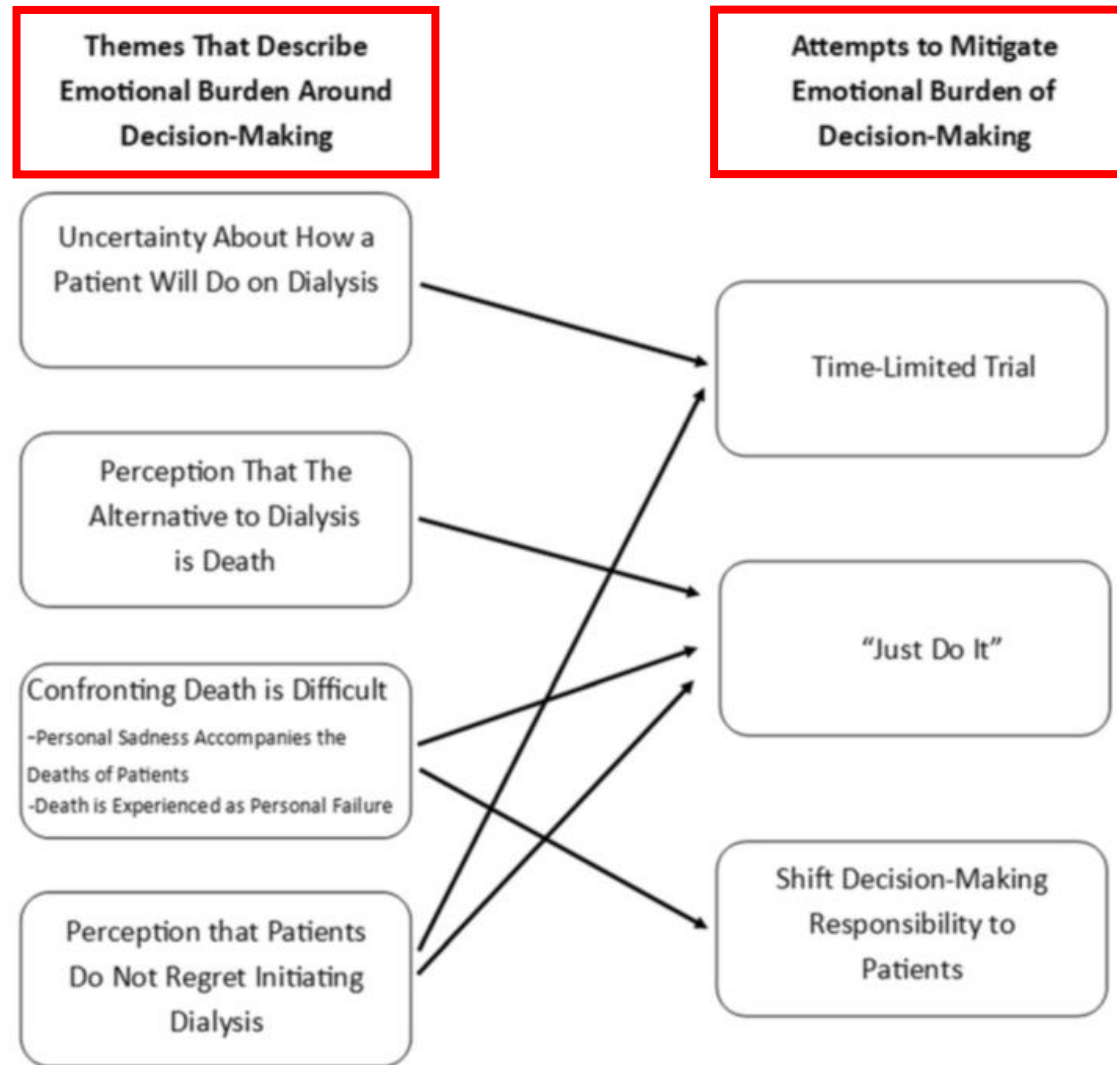
# Moral Distress, Moral Resilience



# Challenges and moral distress for nephrologists in sub-Saharan Africa over prior 2 years (2017)



# Emotional burden - nephrologists

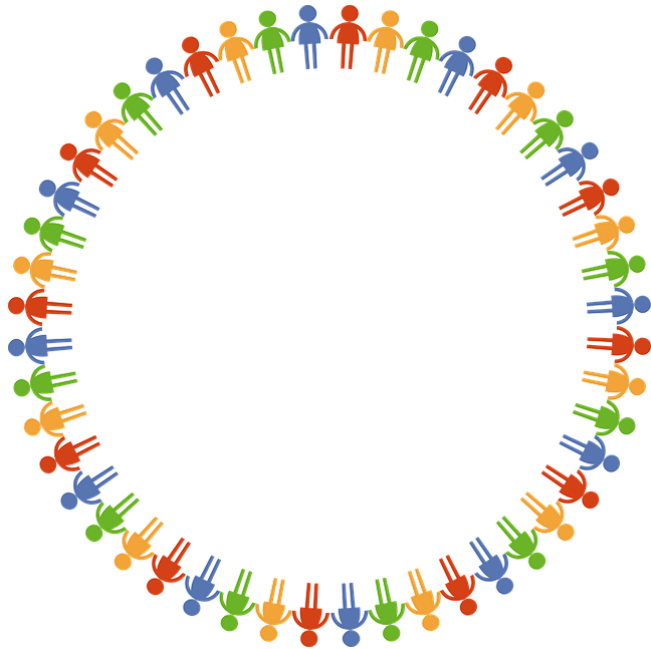




# Supporting moral resilience



- Culture of ethical practice
- Support individuals
- Skilled facilitators, ethics consultants
- Representation on ethics committees
- Educate professionals
- Improve work environment
- Promote collaboration
- Interprofessional strategies to improve communication, support
- Advocate to fix underlying problems – change policy



# National, community challenges - justice

# Kidney health inequalities

## The Facts

UK

**PEOPLE FROM LOWER SOCIO-ECONOMIC GROUPS ARE MORE LIKELY TO:**

**DEVELOP  
CHRONIC  
KIDNEY  
DISEASE**

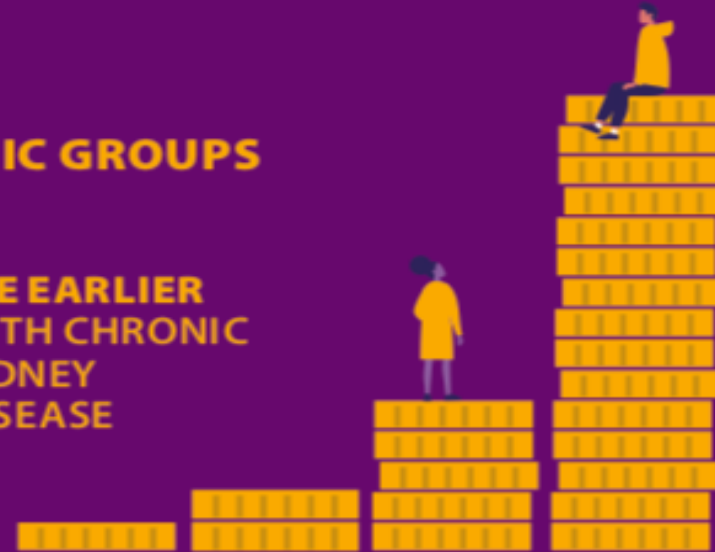


**PROGRESS  
FASTER  
TOWARDS  
KIDNEY FAILURE**



**DIE EARLIER  
WITH CHRONIC  
KIDNEY  
DISEASE**

KIDNEY DISEASE MAY ALSO CONTRIBUTE TO SOCIAL DEPRIVATION



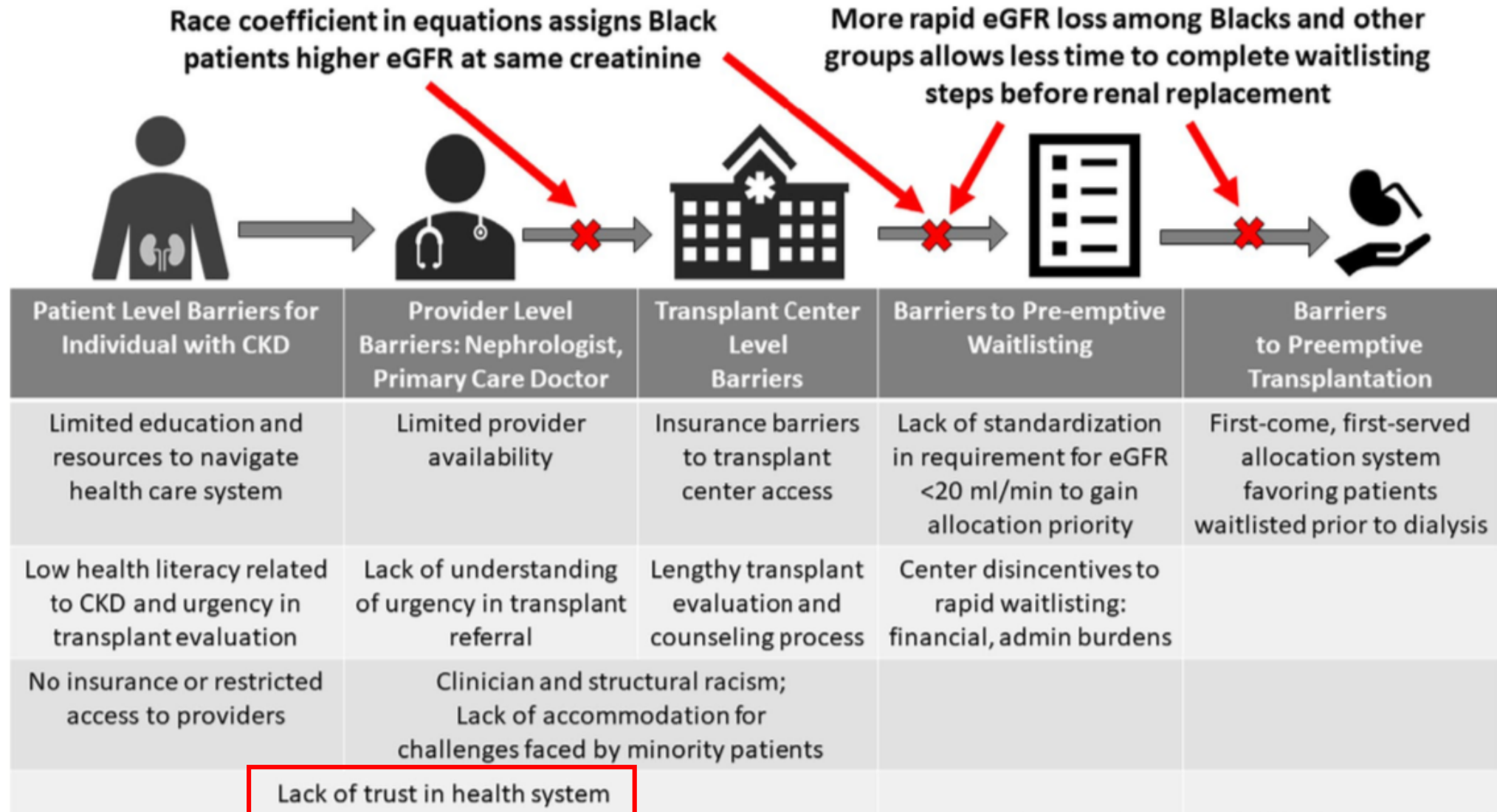
**PEOPLE FROM BLACK, ASIAN AND MINORITY ETHNIC POPULATIONS**



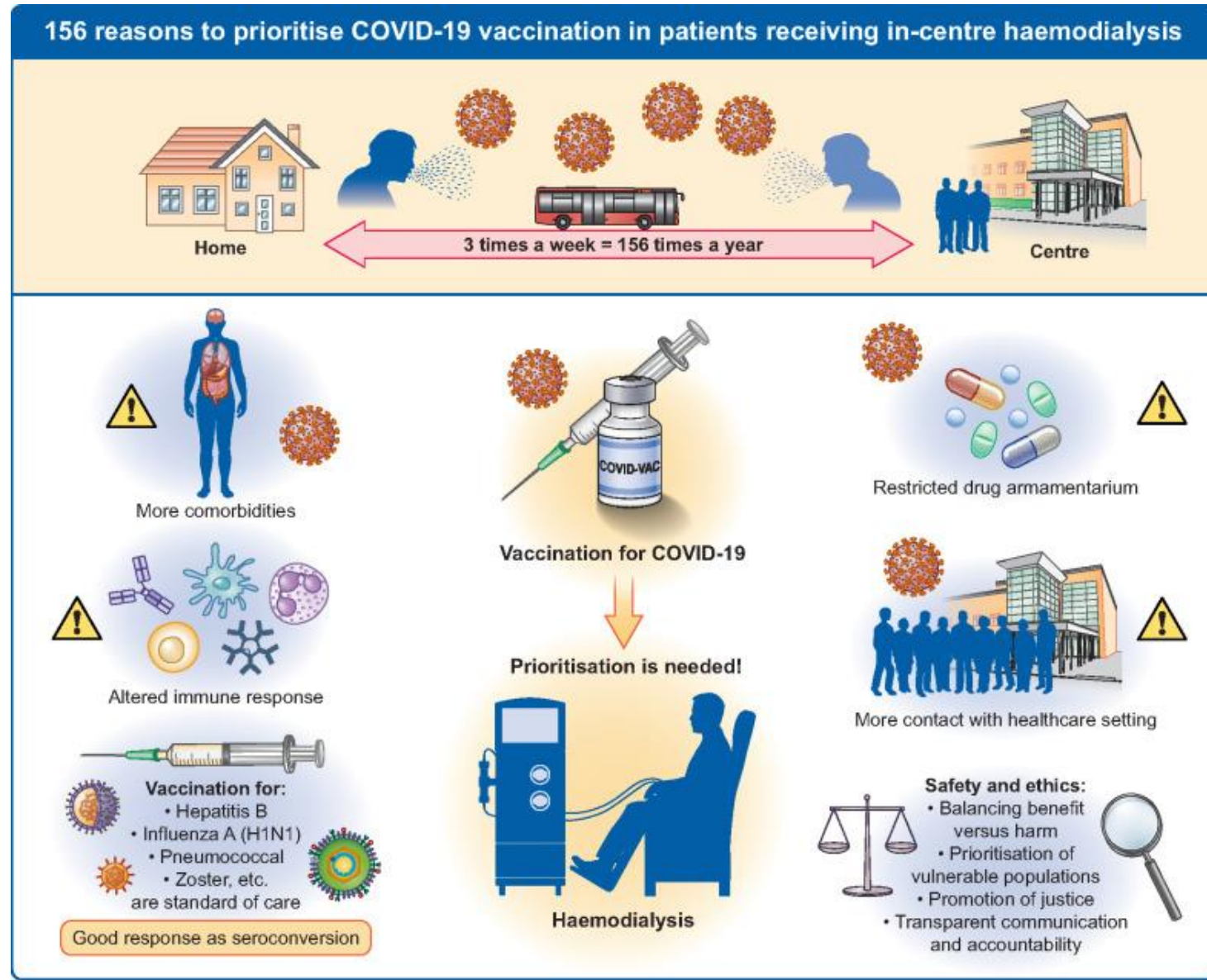
**ARE LESS LIKELY  
TO RECEIVE A  
KIDNEY TRANSPLANT**



# Inequitable listing for preemptive transplantation



# ADVOCACY







# Global challenges - justice

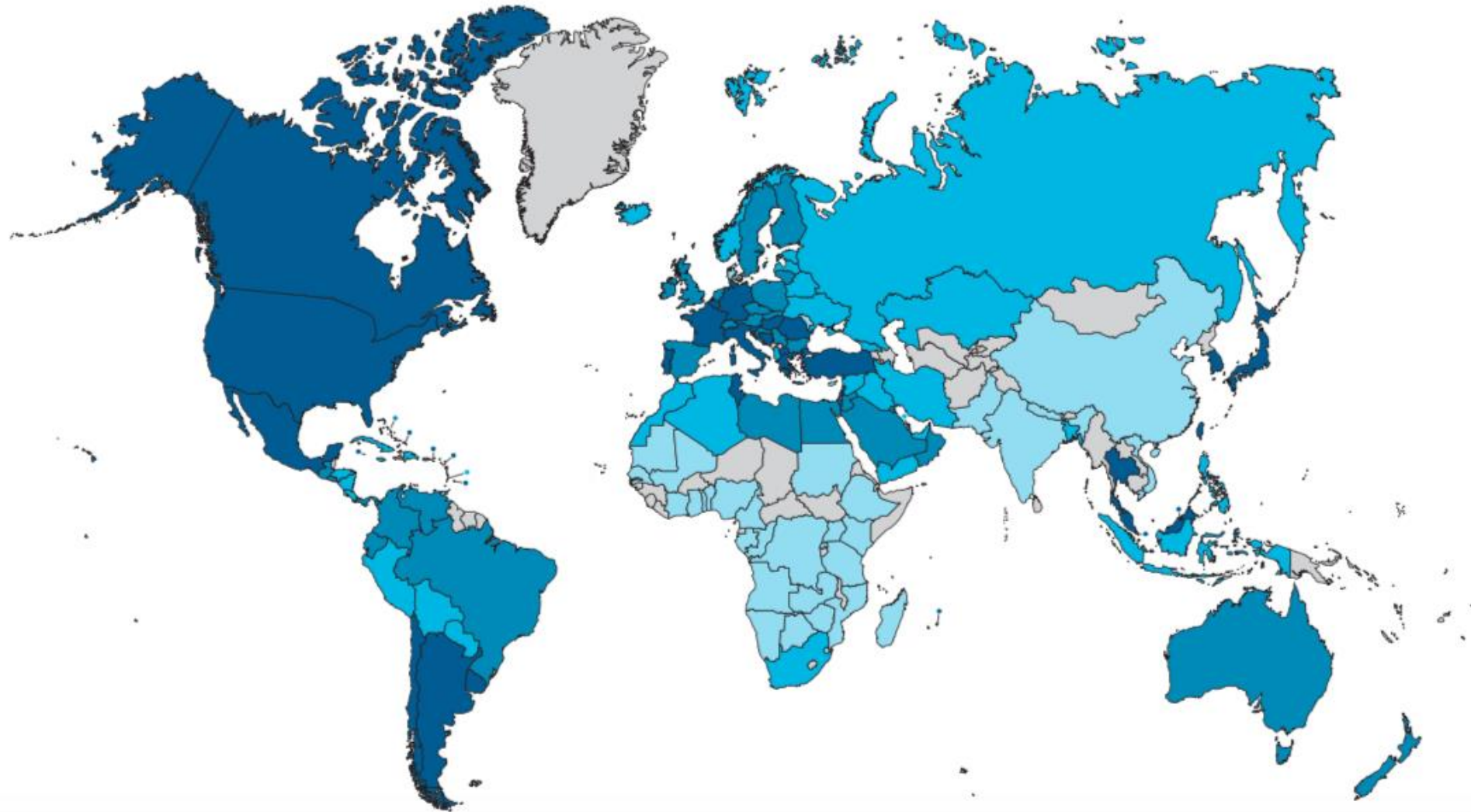
## COVID-19: UN Secretary-General says the world has failed an ethics test

21/09/2021



**“This is a moral indictment of the state of our world. It is an obscenity. We passed the science test. But we are getting an F in Ethics”**

# Global prevalence of chronic dialysis



<https://www.theisn.org/initiatives/global-kidney-health-atlas/>

Rate per million population (pmp), age  $\geq 18$  years

■ <108.4 pmp    ■ 108.4–343.0 pmp    ■ 343.1–632.0 pmp    ■ >632.0 pmp    ■ Data not reported



# Inequities in need for dialysis - everywhere



**Table 1.** ESKD Incidence and Prevalence 2018<sup>8</sup>

	Incident ESKD, Cases per Million	Prevalent ESKD, Cases per Million
Black/African American	834.1	5,854.8
American Indian or Alaska Native	504.4	3,163.4
Asian	355.7	2,275.3
White	312.7	1,703.5

Incidence and prevalence of ESKD in 2018 by race as defined in the US Renal Data System.

Abbreviation: ESKD, end-stage kidney disease.

**Table 2.** Rates of ESKD in Other Racially and Ethnically Diverse Nations

Nation	Disparity
Australia	6.2× greater risk for indigenous people <sup>52</sup>
United Kingdom	3× to 5× greater risk for blacks and South Asians <sup>53</sup>
Canada	2.5× to 4× greater risk for First Nations people <sup>54</sup>

Abbreviation: ESKD, end-stage kidney disease.

# Take home points

## 1. Ethics is about thinking

## 2. Ethics is about communication

- Establishing a shared decision-making relationship
- Informing patients
- Facilitating Advance Care Planning
- Making a decision (e.g. to not initiate or to discontinue dialysis)
- Resolving conflicts about what (dialysis) decisions to make

## 3. Ethics is about transparency and accountability

## 4. Ethics is about fairness

- Awareness of inequities
- Striving to reduce inequities



# Selected references

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- Luyckx VA, Miljeteig I, Ejigu AM, Moosa MR. Ethical Challenges in the Provision of Dialysis in Resource-Constrained Environments. Semin Nephrol. 2017 May;37(3):273-286.



# Question 1: which elements are good practice to ensure informed consent

- A. The task of obtaining informed consent can be delegated to medical students when the nephrology staff are too busy
- B. The patient is able to express/communicate a choice or preference
- C. The patient can give a rational reason for their decision even if against medical advice
- D. The physician must explain the benefits of the proposed treatment, risks need not always be disclosed if too frightening for the patient



## Question 2: Which statements are correct regarding equality and equity?

- A. **Equity:** Everyone must be treated equally
- B. **Equality:** equals must be treated equally, unequals must be treated unequally
- C. **Equality:** everyone must be treated equally
- D. **Equity:** equals must be treated equally, unequals must be treated unequally



# Answers

**Question 1:** B and C

**Question 2:** C and D

