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Clinical Ethics and Nephrology

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Clinical Focus

- General Nephrology
- Nephrology and Palliative Care / Ethics
- Geriatric Nephrology
- Alport Syndrome / Genetic Kidney Disease

DISCLOSURES

I have no relevant financial relationships with ineligible companies.

OBJECTIVES

- Review the relevant history of dialysis care and coverage in the US
- Understand and apply ethical frameworks relevant to nephrology
- Discuss strategies to navigate challenging inpatient nephrology cases

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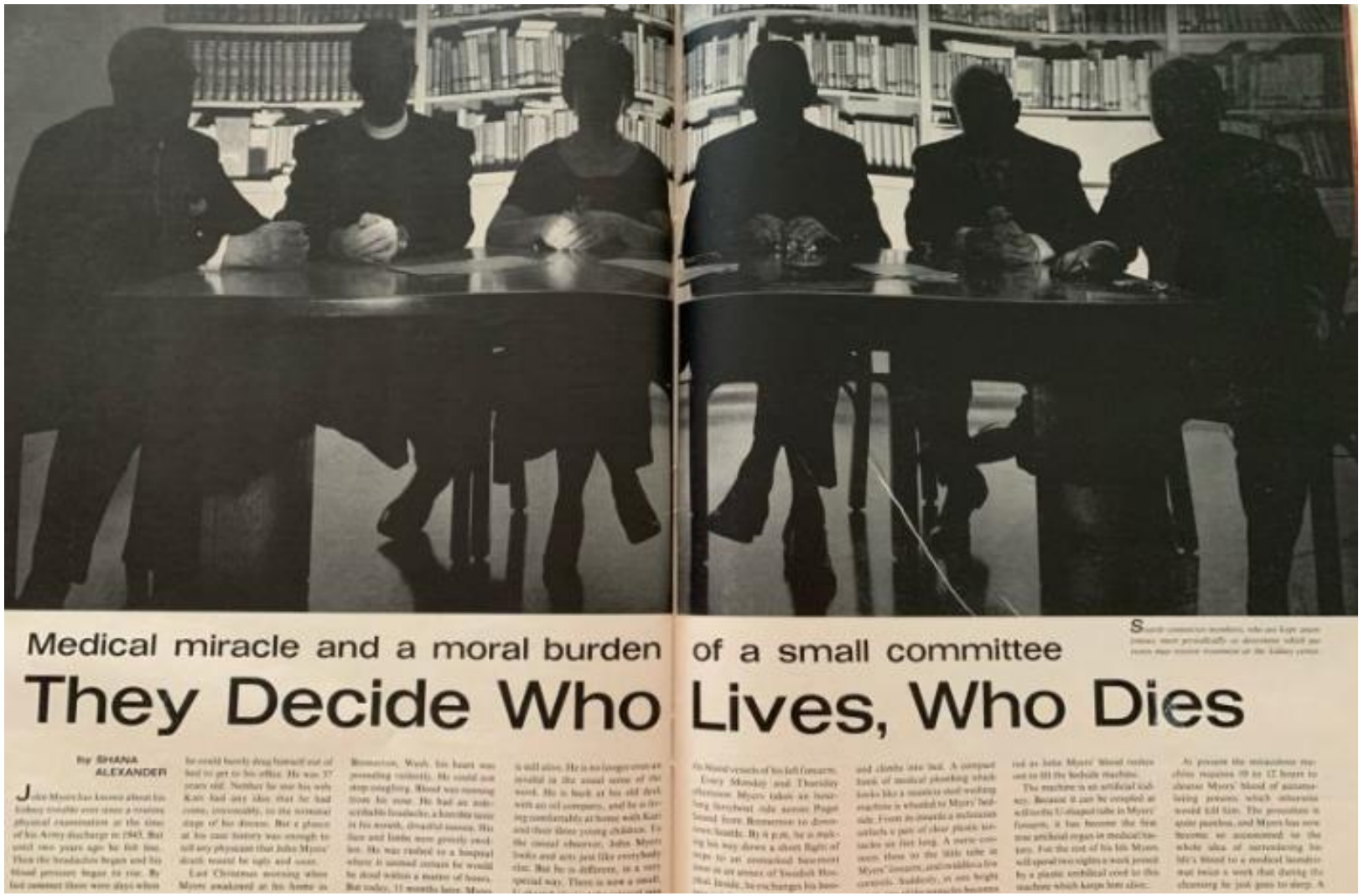
"Unsustainable trends cannot be sustained"

The History of Dialysis in the United States

“God Panels”



Medical miracle and a moral burden

They Decide Who

of a small committee

Lives, Who Dies

By SHANA ALEXANDER

God Panels and Medicare

- 1960s – dialysis allocated based on a patient's "social worth"
  - **Seattle Artificial Kidney Center** – tasked a team of physicians, nurses, and community members/civic leaders to lead an allocation committee
  - Social worth was tied to contribution to the community/world if their life was saved by dialysis
  - Subjective; significant ethical issues immediately
- NIH Director raised concerns that dialysis would save lives, but *at high cost to the country and individual*
- Expose in Life magazine brought this to national attention

God Panels and Medicare

- **1967**- Committee on CKD met in response to this
  - Recommended that ESRD funding come from the federal government
  - Decided under the premise that most patients "medically suitable for dialysis" would be under 54 years old with few comorbidities
- **1972 –** Escalating rates of renal failure, Congress expanded legislation to provide lifelong subsidization for dialysis to all patients with ESRD[2]
  - Significant underestimation of cost; at the time of enactment 10,000 patients on dialysis (280 millions) but this has grown exponentially
  - Dialysis to this day occupies > 7-8% of the Medicare budget[3]

Historic questions remain relevant today

- Costs continue to rise exponentially
- Annual Medicare spending in excess of $30 billion for dialysis care[3]
- Since 2003, the number of frail elders > 80 years old initiating HD have been steadily increasing[4]
  - Mortality remains high[4]
  - Robust data suggest that dialysis in elders in nursing home is associated with drastic decline in functional status and QOL[5]
- Prevalence of autonomy in US medical ethics
- Decline in provider-patient trust post-Covid pandemic

A potential crisis of dialysis care looming in the US- how do we navigate this?

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Ethical Frameworks for Nephrology

Frameworks to guide practice

- Reduce bias
- Navigate complexity in a standard fashion
- Reduce moral distress

Principlism

- **1970s -** The *Belmont Report* and the *Principles of Biomedical Ethics* established four bioethical principles to guide medical decision-making[6,7]
  - Respect for persons (i.e. autonomy)
    - The right to self-determination
  - Beneficence
  - Non-maleficence
  - Justice (respect for persons)
- US Ethics in particular relies on this framework
  - Patient patient / family autonomy drive medical decision making
- With rise of *principlism*, "paternalism" has been in decline
  - We must consider if this has come with abdication of the role of physicians
  - Do patients get to choose all aspects of care?
  - Benefit vs. burden analysis – who quantifies suffering?
    - Patients with kidney disease have higher distress and critical illness tolerance; lower baseline[8]

Application of Principlism

An 86-year-old female with CKD V, HTN, DM, HFrEF (EF 20%), PAD, and mild neurocognitive impairment presents with AKI on advanced CKD with refractory hyperkalemia and volume overload. She lives in a nursing home. Her family reports excellent quality of life, though she does not leave her wheelchair. Her baseline BP is in the 90s and you are worried about dialysis tolerance. Her family is confident she would want to live “every possible day” and is strongly advocating for dialysis initiation.

How might you apply ethical principlism to this case?

Case Continued

- **Autonomy**
  - The patient gets to decide
  - Her family is clear on her wishes
  - The patient and her family can understand the nephrologists concerns and then make an informed decision
  - Shared decision making
- **Beneficence / Non-Maleficence**
  - The nephrologist has real concerns about dialysis tolerance
  - Dialysis initiation would almost certainly lead to decline in functional status and quality of life
  - Can the patient truly represent her interests given dementia?

What would likely happen?

- Dialysis would be initiated
- Conflict avoided
- “Patient centered” care approach that favors autonomy
- At what cost? Is this the correct approach?
  - These principles require iterative re-application as cultural and societal expectations evolve for critically ill patients
- *2010 RPA Guidelines* provide support for withholding dialysis in certain cases[9]
  - Advanced dementia / agitation, malignancy or other conditions with very poor prognosis, mental illness such that dialysis cannot be provided safely

Substituted Judgment

- Ethical framework helpful when a patient is incapacitated or unable to otherwise articulate their wishes
  - Posited to return autonomy to an incapacitated patient
- Requires extrapolation of a patient's known values, preferences, and prior life choices to inform a decision never previously queried
- Can be helpful in states (such as MA, NY) with complicated surrogate decision-making laws
- Highly relevant as up to 47% of adults require surrogate decision making within 48h of hospitalization[10]

Limitations to Substituted Judgment

- Overly prioritizes longevity which may not be in the best interest of the patient[11, 12, 13]
- May conflict with familial / cultural beliefs[11,12, 13]
- Inherently subjective
- When studied retrospectively, our “best guess” at what a loved one would want is often wrong
  - Spouses unsuccessful at predicting their partner’s preference for dialysis in various hypothetical scenarios[14]
- There often is no alternative to utilizing this in some capacity

Substituted Judgment Case

A 63-year-old male with schizophrenia with psychotic features, HTN, T2DM (refuses insulin, A1c 11.3%) who is experiencing homelessness presents to the ED with acute renal failure necessitating RRT consideration urgently. The patient's friends from his shelter are present and endorse certainty that the patient would never want dialysis. His PCP notes document life-long reticence for medical care and limited engagement with outpatient providers.

How might you apply substituted judgment to this case?

Case Application

- The patient's decisions across his life suggest he would not want aggressive care nor to engage with the system regularly
  - PCP appointments, insulin adherence, stated preferences
- A decision to recommend against dialysis is ethically permissible
- Efforts should be made to:
  - Assess for any dissenters
  - Discuss with longitudinal providers
  - Obtain collateral
  - Ensure no undue influence or secondary gain from collateral sources

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Strategies for Challenging Inpatient Dialysis Cases

Strategies to Consider

- Time-limited trials of dialysis[15, 16]
  - Rarely work
  - Must be thoughtfully enacted with clear exit ramp and patient/family/provider trust
  - Challenging to uphold with frequent care transitions
  - May be over-utilized to forgo difficult goals of care discussions
- Early consideration of palliative care introduction
- Honest discussion of data at the time of initiation
  - Particularly special populations - ESLD, cancer, s/p BMT
- Application of shared decision-making frameworks
  - REMAP/Serious Illness Conversation Guide[17, 18]

Mitigating Distress

- Nephrologists increasingly asked to navigate conflict/complexity
- Patient/family distrust rising balanced with our professional expertise
- Seemingly no limit to “acceptable suffering”
  - Challenging to witness
  - Challenging to manage
  - Challenging to provide
- Worries about sustainability
- Divisional support, hospital policy, and national leadership are necessary while also providing peer support
- Case-based discussions may be helpful

TAKE HOME MESSAGES

- Ethical challenges are rising in nephrology as patients age and cases become challenging
- This is a difficult time with significant distress in our field
- Nephrologists can use substituted judgment and principlism to support ethical decision making
- Caution should be exercised with time-limited trials
- National and institutional standards are necessary to guide decision making on dialysis provision
  - Including sustainable payment plans

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Thank you!

REFERENCES

1. Ross, W. (2012). *God panels and the history of hemodialysis in America: A cautionary tale*. *AMA Journal of Ethics, 14*(11), 890–896. https://doi.org/10.1001/virtualmentor.2012.14.11.mhst1-1211
2. United States Congress. (1972). *Public Law 92-603, Social Security Amendments of 1972*, 86 Stat. 1329. https://www.govinfo.gov/content/pkg/STATUTE-86/pdf/STATUTE-86-Pg1329.pdf
3. United States Renal Data System. (2024). *2024 USRDS annual data report: Epidemiology of kidney disease in the United States, Chapter 9: Healthcare expenditures for persons with ESRD*. National Institute of Diabetes and Digestive and Kidney Diseases. https://usrds-adr.niddk.nih.gov/2024/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd
4. Sladoje-Martinovic B, Mikolasevic I, Bubic I, Racki S, Orlic L. Survival of chronic hemodialysis patients over 80 years of age. Clin Interv Aging. 2014 Apr 16;9:689-96. doi: 10.2147/CIA.S58976. PMID: 24790421; PMCID: PMC3998852.
5. Kurella Tamura, M., Covinsky, K. E., Chertow, G. M., Yaffe, K., Landefeld, C. S., & McCulloch, C. E. (2009). Functional status of elderly adults before and after initiation of dialysis. *The New England Journal of Medicine, 361*(16), 1539–1547. https://doi.org/10.1056/NEJMoa0904655
6. Protections (OHRP) O for HR. The Belmont Report. January 28, 2010. Accessed April 2, 2026. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html
7. Beauchamp T, Childress J. *Principles of Biomedical Ethics*. 1979.
8. Nisula S, Vaara ST, Kaukonen KM, et al. Six-month survival and quality of life of intensive care patients with acute kidney injury. *Crit Care*. 2013;17(5):R250. doi:10.1186/cc13076
9. Renal Physicians Association: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis.
10. Torke AM, Sachs GA, Helft PR, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Intern Med*. 2014;174(3):370-377. doi:10.1001/jamainternmed.2013.13315
11. Wierenga E. Proxy Consent and Counterfactual Wishes. *J Med Philos Forum Bioeth Philos Med*. 1983;8(4):405-416. doi:10.1093/jmp/8.4.405
12. "What the patient would have decided": A fundamental problem with the substituted judgment standard | Medicine, Health Care and Philosophy | Springer Nature Link. Accessed April 2, 2026. https://link.springer.com/article/10.1007/s11019-006-9042-2
13. Chan HM. Sharing death and dying: advance directives, autonomy and the family. *Bioethics*. 2004;18(2):87-103. doi:10.1111/j.1467-8519.2004.00383.
14. Pruchno RA, Rovine MJ, Cartwright F, Wilson-Genderson M. Stability and change in patient preferences and spouse substituted judgments regarding dialysis continuation. *J Gerontol B Psychol Sci Soc Sci*. 2008;63(2):S81-91. doi:10.1093/geronb/63.2.s81
15. JS, Jl H. The Role of Time-Limited Trials in Dialysis Decision Making in Critically Ill Patients. *Clin J Am Soc Nephrol CJASN*. 2016;11(2). doi:10.2215/CJN.03550315
16. Saeed F, Duberstein PR, White DB, Liu KD, Epstein RM, Fiscella KA. Time-limited trials for acute dialysis decision-making for critically ill older patients: rationale, communication strategies, and future research. *Curr Opin Nephrol Hypertens*. 2026;35(2):195-201. doi:10.1097/MNH.0000000000001155
17. Mandel EI, Bernacki RE, Block SD. Serious Illness Conversations in ESRD. *Clin J Am Soc Nephrol CJASN*. 2017;12(5):854-863. doi:10.2215/CJN.05760516
18. Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. *J Oncol Pract*. 2017;13(10):e844-e850. doi:10.1200/JOP.2016.018796