

MORAL DISTRESS IN NEPHROLOGY

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OUTLINE

1. Background

2. Case Scenarios

3. Implications and approach for clinicians

MY JOURNEY



COMPLEXITY AT END OF LIFE

- Many older patients with ESKD have multiple comorbidities¹, frailty,² reduced functional status³ and cognitive impairment⁴ all of which ↓ prognosis
- Increasing complexity of care including treatment decision making at end of life
- Increasing time and resources required to provide optimal care⁵

1. Foote et al. NDT 2012

2. Swindler, JASN 2013

3. Cook et al. KI 2008

4. Tamura et al. CJASN 2015

5. Tonelli et al. JAMA 2018

QUESTIONS RAISED

Challenges around treatment decision making in our population of patients who are older, multi-morbid and medically complex

- How best to treat?
- When to change approach and consider treatments as potentially futile?
- Why have I felt at times that I am part of a system that may not be providing optimal end of life care for renal patients?

I am alone?



I am alone?



PhD: Renal clinicians' views and experiences of palliative care, supportive care and end of life care



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MELBOURNE

MORAL DISTRESS

Concept described in 1984 by Jameton

Circumstances where one knows the “right thing to do” but institutional constraints make it nearly impossible to pursue the right course of action¹

MORAL DISTRESS

Originally described in critical care nursing

Perception of patients suffering from inappropriate medical treatments & an inability to act on this moral judgment

Erodes professional & personal integrity

eg. Resuscitating a patient who is dying from multi-organ failure

MORAL DISTRESS ≠ ETHICAL DILEMMA

	Example	Ethical Dilemmas	Moral Distress
Dialysis treatment decision making	A patient with advanced dementia has develops ESKD and their family request dialysis	<p>Potential harm Vs benefit of treatment</p> <p>Resource allocation in health care system</p>	<p>Dialysis viewed as not ethically appropriate but is commenced due to:</p> <ul style="list-style-type: none">- family influences- acute on chronic renal impairment & dialysis as “default”- financial incentives



Moral Distress Amongst American Physician Trainees Regarding Futile Treatments at the End of Life: A Qualitative Study

Elizabeth Dzung, MD, MPH, MPhil, MS^{1,2,3,4}, Alessandra Colaianni, M.D., M.Phil.¹,
Martin Roland, B.M., B.Ch., D.M.³, David Levine, M.D., M.H.S., Sc.D.¹, Michael P. Kelly, Ph.D.³,
Stephen Barclay, B.M., B.Ch., M.D.³, and Thomas J. Smith, M.D.^{2,5}

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Society of General Internal Medicine 2015

“We do a lot of terrible things to critically unwell people at the end of life. It’s routine care, and I feel pretty numb to having done those things... It seems like there is no benefit and only risk. Yet I am accepting the patients to have these procedures done to them. I’m in that situation all the time. I’m pretty powerless to do anything about it.” (B, PGY-4)



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- Themes of suffering, emotional angst, powerlessness, desensitisation, hierarchical barriers “unable to question”
- Successful coping strategies of formal and informal debriefing forums

Ethical Issues in Palliative Care

Moral Distress at the End of a Life: When Family and Clinicians Do Not Agree on Implantable Cardioverter-Defibrillator Deactivation



Jill M. Steiner, MD, Kristen K. Patton, MD, Jordan M. Prutkin, MD, MHS, and James N. Kirkpatrick, MD
Division of Cardiology (J.M.S., K.K.P., J.M.P., J.N.K.), University of Washington, Seattle, Washington; and Department of Bioethics and Humanities (J.N.K.), University of Washington, Seattle, Washington, USA

- Implantable cardiac defib, recurrent and painful shocks in refractory VT at EOL
- Patient did not have capacity to make their own decisions
- Turning off the ICD would be to commit an act that causes death -- family
- Turning off the ICD would relieve suffering in a man who is dying -- medical

Clinicians' Perspectives on Providing Emergency-Only Hemodialysis to Undocumented Immigrants

A Qualitative Study

Lilia Cervantes, MD*; Sara Richardson, RN*; Rajeev Raghavan, MD; Nova Hou; Romana Hasnain-Wynia, PhD; Matthew K. Wynia, MD; Catherine Kleiner, PhD, RN; Michel Chonchol, MD; and Allison Tong, PhD

Ann Intern Med. doi:10.7326/M18-0400

Annals.org

For author affiliations, see end of text.

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* Dr. Cervantes and Ms. Richardson contributed equally to this work.

- Qualitative study of 50 clinicians providing emergency only dialysis (USA)
- Guilt, emotional & physical exhaustion from witnessing needless suffering and mortality
- Moral distress from “propagating injustice”
- Making treatment decisions based on non clinical factors (social status)

Some cases in Nephrology & discussion

MORAL DISTRESS & TREATMENT DECISION MAKING

Case 1.

An 80-year-old man with advanced heart failure, diabetes and peripheral vascular disease slowly progressed to ESKD.

- Together the patient and renal team decide on conservative care*
- He becomes increasingly symptomatic and his daughter insists her father has not completely understood implications of his renal failure and treatment decisions and now they are requesting dialysis*
- After further discussion the patient and daughter understand the risks and benefits of starting dialysis, so he starts urgent haemodialysis*

MORAL DISTRESS & TREATMENT DECISION MAKING

Case 1. Discussion

- *If he deteriorates, moral distress may amplify*
- *Potential contributing factors:*
 - *Uraemic complications*
 - *Family influence*
 - *Healthcare system to start dialysis as “default”*
 - *Uncertainties of cognition and capacity*

Discussing Conservative Management With Older Patients With CKD: An Interview Study of Nephrologists



Keren Ladin, Renuka Pandya, Allison Kannam, Rohini Loke, Tira Oskoui, Ronald D. Perrone, Klemens B. Meyer, Daniel E. Weiner, and John B. Wong

- Qualitative study 35 nephrologists (USA)
- 37% routinely discussed CM as a treatment option

Complete author and article information provided before references.

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*Am J Kidney Dis. 71(5):
627-635. Published online
February 3, 2018.*

Factors Associated with Nephrologists decisions to discuss CM:

- View it as their role to discuss CM with all patients
- Proactive in EOL conversations
- Communication with family members
- Patients engaged in decision making
- Strong institutional support
- Salient experiences with moral distress

MORAL DISTRESS & WITHDRAWAL FROM DIALYSIS

Case 2.

An 85-year-old woman with mild dementia and hypertension who lived at home with her husband developed ESRD.

- After discussions with her nephrologist and husband, she commenced haemodialysis*
- She falls and sustains a pelvic fracture, has a long admission and significant ongoing pelvic pain, immobility, cognitive deterioration and she is placed in a nursing home*
- The dialysis staff describe seeing her deteriorating, often in pain and suffering and feel unable to raise the possibility of stopping dialysis with her husband or her nephrologist*

MORAL DISTRESS & WITHDRAWAL FROM DIALYSIS

Case 2. Discussion

- *Issues of patient advocacy*
- *Potential contributing factors:*
 - *limited supports / integration with pall care*
 - *hierarchical structures / professional roles*
 - *communication between team members*
 - *fear of being misunderstood*

MORAL DISTRESS & POWER DYNAMICS

Case 3.

A 79-year-old woman with advanced CKD from diabetic nephropathy has a large abdominal aortic aneurism

- She has an urgent endovascular aneurism repair complicated by vasodilatory shock and aneuric renal failure in ICU*
- The nephrology service is consulted to “start dialysis”*
- The patient’s family is distraught and tell the renal registrar that she would not want dialysis, especially if she would remain dialysis-dependent*

MORAL DISTRESS & POWER DYNAMICS

Case 3.

When the trainee shares this information with the vascular team, they tell him that he “overstepped a boundary” and it was “not his job to discuss goals of care”

The surgical and nephrology consultants discuss directly with her family and dialysis is initiated

The patient experiences several complications and after 2 weeks suffers a stroke and dies

MORAL DISTRESS & POWER DYNAMICS

Case 3. Discussion

- *Powerlessness & professional role*
- *Potential contributing factors:*
 - *Conflicting values*
 - *Hierarchical pressure to conform*
 - *Communication across multiple teams*
 - *Expectations for dialysis*

MORAL DISTRESS & RESOURCE LIMITATIONS

Case 4.

The South African health system has a private sector with universally available dialysis; and a public sector (dialysis is available only for people eligible for renal transplant)

A 32-year-old man with three children presents with ESKD. He has no private insurance and he is not possible to transplant therefore is ineligible for dialysis

The nephrologist must explain this to him, and to other patients like him every day

MORAL DISTRESS & RESOURCE LIMITATIONS

Case 4. Discussion

- *Inability to provide adequate healthcare due to social status*
- *Disconnect between ethical decision making and financial / system constraints*
- *Powerlessness of individuals against a system*

IMPLICATIONS OF THESE SCENARIOS

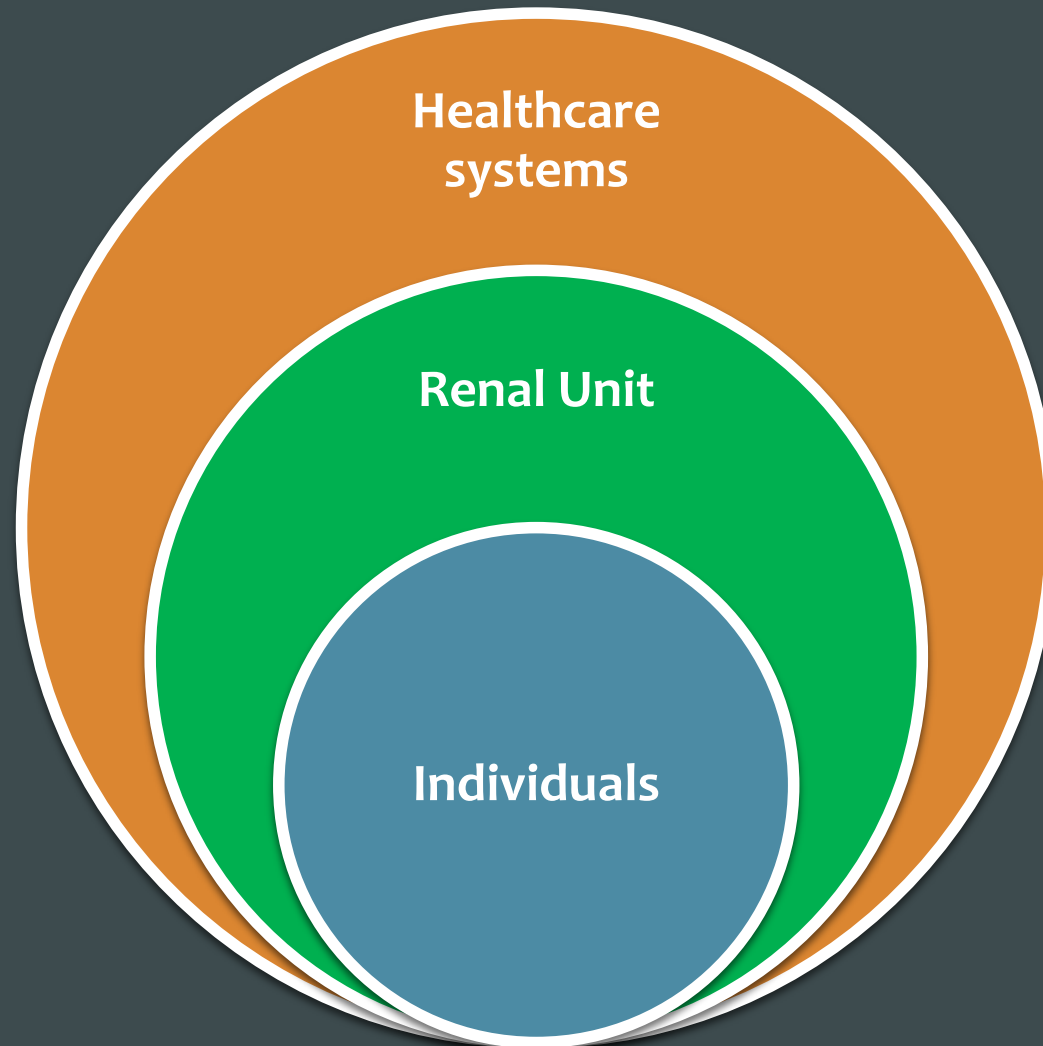
These situations can be highly emotional, uncertain and challenge our integrity as doctors, nurses, caregivers.

For clinicians, moral distress can result in:

- Frustration, hurt, guilt and anger¹
- Detachment, desensitisation, dehumanisation²
- Burnout³
- Absenteeism / Career compromise / leave profession

1. Sundin-Huard & Fahey, 1999
2. Dzung et al. 2015
3. Cervantes et al, 2018

WAYS TO ADDRESS MORAL DISTRESS



WAYS TO ADDRESS MORAL DISTRESS



Individuals

1. Acknowledgement
2. Courage & Leadership
3. Using evidence to inform and discuss decisions

WAYS TO ADDRESS MORAL DISTRESS



**Renal
Units**

1. Culture of respect & communication
2. Senior staff leadership
3. Institutional support for further research to inform decisions

WAYS TO ADDRESS MORAL DISTRESS



Healthcare
systems

1. Anticipating moral distress
2. Ethical support & education for clinicians
3. Healthcare policies that promote clinical, ethical and financial cohesion

MORAL DISTRESS

1. Individualised and subjective
2. The perception of not being able to act ethically due to external constraints
3. In the literature, most commonly adversarial end of life scenarios & lack of resources for adequate care
4. Has lasting implications for clinicians and health care services if not acknowledged and addressed

CONCLUSIONS

Challenges around treatment decision making and end of life care in our population of renal patients who are older, multi-morbid and medically complex

- Variable systems and resources in place for supporting clinicians , patients and families in end of life decision making
- This may increase the risk of moral distress in our clinical practice

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A one day academic event for renal and palliative care clinicians

Program will include:

- Complex symptom management in ESKD
- An evidence based approach to decision making, conflict & resilience
- Models and outcomes of Renal Supportive Care programs

Friday 29th November

**@ St Vincent's Hospital
Melbourne**

Registration & info:

<https://www.centreforallcare.org>

Renal Supportive Care Master Class 2019

Supported by:  Renal Society of Australasia  ANZJPM  Centre for Palliative Care

Renal & Hypertension Service
St George & Sutherland Hospitals



Pallmed Research Group

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