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Moral Distress in Nephrology: Perceived Barriers to Ethical Clinical Care
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To the Editors of the American Journal of Kidney Disease,

Thank you for the opportunity to be re-considered for a submission of a perspective piece in AJKD titled:

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The authors have considered and responded to the reviewer's comments within the manuscript document and are grateful for the advice and counsel in developing this important paper and topic in renal medicine.

If you need any further details or clarification, please do not hesitate to contact me.

Kind regards,

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Commented [DK2]: Thank you we have added a third Figure including specific suggestions for institutions and individuals. (Figure 3) see last page of manuscript

Title Page

Title: Moral distress in Nephrology: perceived barriers to ethical clinical care

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Abstract

Moral distress occurs when individuals are unable to act in accordance with what they believe to be ethically correct or just. It results from disparity between a clinician's perception of "the right thing to do" and what is actually happening, and is perpetuated by perceived constraints that limit the individual from speaking up or enacting change. Moral distress is reported by many clinicians in caring for patients with serious illness, including chronic kidney disease and kidney failure. If left unidentified, unexpressed or persistent, moral distress may cause burnout, exhaustion, detachment and ineffectiveness. At an extreme, it may lead to a desire to abandon the speciality entirely. This article offers an international perspective on moral distress in nephrology in diverse contexts and health care systems. We examine and discuss the sociocultural factors that contribute to moral distress in nephrology and offer suggestions for interventions from individual provider, facility, and healthcare systems perspectives to reduce the impact of moral distress on nephrology providers.

Introduction

Moral distress occurs when individuals are unable to act according to their ethical beliefs due to external factors [1]. Moral distress is not a difference of opinion or ethical dilemma where parties debate merits of actions and choose solutions (Figure 1). In nephrology, moral distress exists in many forms and is universally experienced as profound frustration and compromised integrity stemming from inability to pursue their perceived ethical course of action [2].

If moral distress is constantly and repeatedly felt, it disenfranchises clinicians and ultimately erodes professional joy of patient care. Epstein and colleagues stated: “It is not appropriate to expect highly skilled, dedicated and caring healthcare professionals to be repeatedly exposed to morally distressing situations when they have little power to change the system and little acknowledgement of these experiences as personally damaging or career compromising” [3]. Sources of moral distress may remain unspoken, and, if unexpressed, moral distress leads to resentment, anger, and dissatisfaction. When repeatedly experienced, moral distress may crescendo to a high sense of disillusionment and burnout [4]. These consequences unavoidably effect professional and patient experiences of care.

Background

The concept of moral distress was first described by Jameton in critical care nurses feeling unable to act ethically due to institutional limits [5]. Over recent decades, moral distress is described in various situations, including decision-making and deactivation of implantable defibrillators and pressures experienced by psychiatrists, performing assessments of capacity near end-of-life [6, 7]. The literature describes scenarios of moral distress experienced by nurses [8, 9], physicians [6, 10], trainees [11], medical students [12] allied health professionals [13, 14] and patients [15]. A common theme is feeling unable to voice

concerns or challenge norms. A norm says “this is the way it has always been” or “this decision is not in your hands.” It is likely patients also experience moral distress ~~as-when~~ circumstances and values are challenged by existing frameworks guiding care. For example, some patients considering withdrawing from dialysis may feel obliged, due to external factors, to continue with aggressive kidney replacement therapy.

We examine moral distress relating to clinicians in nephrology, including attendings, physician trainees and extenders, and nursing staff in diverse situations. Case scenarios adapted from authors’ experiences highlight various sources of moral distress in healthcare systems. We conclude by considering solutions and calling upon the kidney community to promote strategies relieving the burden of moral distress for clinicians of all training and practice backgrounds.

Moral distress and resource constraints

A. In South Africa, there are two health care sectors: the private sector has universally available dialysis while the public sector, ~~which provides care for 80% of the population,~~ has ~~very~~ limited dialysis access. ~~It is estimated that 52.7% of people with ESRD in South Africa are not offered renal replacement therapy based on medical and socio-economic criteria determined by a public hospital assessment committee [16].~~ ~~specifically that dialysis is available only for people eligible for kidney transplant.~~ A 32-year-old man with three children presented ~~to a~~ Nephrology services with chronic kidney failure requiring kidney replacement therapy. He ~~has had~~ no private insurance, ~~is~~ ~~iswas~~ unemployed with a history of substance abuse and he ~~iswas not~~ ~~accepted~~ onto the public hospital program for ~~transplantation or dialysis~~ renal replacement therapy. ~~unemployed with a history of substance abuse and he is not accepted onto the public hospital program for transplantation or dialysis.~~

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7 The nephrologist ~~who~~ is forced to explain to this patient that he will soon die of
8 kidney failure. She ~~7~~ tells her colleagues: “Every day I have to do this (for different
9 patients). I absolutely know he could have dialysis if he had private insurance ... This
10 is eating at my soul.”
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15 B. In the United States of America (USA), undocumented immigrants are ineligible
16 for federal public health insurance, which predominantly pays s for maintenance
17 hemodialysis treatments. Although some states have health insurance systems or
18 charity programs funding hemodialysis, an estimated 30 to 50% of undocumented
19 immigrants receive emergency-only dialysis. A 45-year-old mother of three children
20 ~~has~~ lived in the USA for 4 years when she developeds end-stage kidney failure.
21 Every week she waiteds until she ~~is~~ was vomiting or dyspneic before going to the
22 emergency department, and she ~~has been~~ was turned away many times for being “not
23 sick enough” to need dialysis ~~that day~~. She has had four admissions to intensive care
24 units for pulmonary edema and two cardiac arrests. She worries constantly about
25 dying and what her family will do without her. The emergency medicine and
26 nephrology teams feel disenfranchised and impotent withholding standard, safe, and
27 otherwise available dialysis but for financial, institutional, and political factors.
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40 In both of these cases, there is a powerful disconnect between perceived ethical practice and
41 the delivered clinical practice. This divide erodes both professional and personal integrity and
42 extends beyond the nephrologist to include all members of the treatment team, patients,
43 families and communities. ~~These examples show how kidney care providers are placed in~~
44 ~~positions of needing to withhold dialysis from patients, where it is clinically and ethically~~
45 ~~indicated due to financial restrictions.~~ In their qualitative study of nephrologists’ perceptions
46 on providing emergency-only dialysis for undocumented immigrants, Cervantes et al [17]
47 demonstrated d that this produces physician burnout ~~and, reflecting the~~ moral distress related to
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propagating injustice by care provision based on “non-medical” or external factors [17].

Patients, families and nephrologists ~~can~~ have a profound sense of powerlessness as individuals within such resource constrained systems.

Moral distress and treatment decision making

C. An 80-year-old man with heart failure, diabetes and peripheral vascular disease slowly progressed to kidney failure. Many conversations about treatment choices occurred between the patient and the nephrology team, and together they decided ~~he is~~ was best managed with non-dialysis conservative care. As he ~~becomes~~ became increasingly uraemic and symptomatic, his daughter requested ~~eds~~ an urgent appointment. She insisted ~~eds~~ her father ~~has did~~ not completely ~~understood~~ understand ~~the~~ implications of his kidney failure and treatment decisions and ~~he now~~ he requests dialysis. His nephrologist wondered ~~eds~~ if this change ~~is was~~ truly from the patient, given their multiple past discussions; however as the patient and daughter ~~both are were~~ adamant, so ~~understand risks and benefits of starting dialysis,~~ he initiated ~~eds~~ urgent haemodialysis.

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The nephrologist experienced moral distress when doubting the veracity of sudden and unexpected changes in treatment preferences. He perceived the “right thing” was to abide by the treatment plan they repeatedly discussed, particularly given burdens of dialysis in elderly frail patients with multiple comorbidities. However, he felt constrained by the development of symptoms that likely were due to kidney failure. The case is complicated by potential influences ~~of such as:~~ family preferences, ~~and~~ uncertainties of ~~uraemia affecting~~ cognition, ~~and decision making capacity~~ and consent ~~with advanced uraemia, and healthcare systems readily able to provide dialysis.~~ However, if the patient deteriorated on dialysis, moral distress for the clinician may be amplified resulting from this treatment decision. Wong and

Commented [A8]: Reconcile with the vignette. - amended

colleagues used qualitative analyses of medical records to ~~A recent qualitative study~~
investigate the practises of nephrologists when patients chose a conservative management
pathway compared with dialysis. They described an “all or nothing” treatment approach for
older patients with advanced CKD and dialysis initiation was a powerful default option with
few perceived alternatives [18]. - This ~~could~~ reflects the stark contrast of systems, resources
and approach between dialysis and conservative management in clinical practice for some
nephrologists. If the patient deteriorates on dialysis, moral distress may be amplified
resulting from this treatment decision.

Commented [A9]: Can you flesh this concept out a bit more?

Commented [DK10]: Yes, added more explanation and discussion

Moral distress and withdrawal from dialysis

- D. An 85-year-old woman with mild dementia and hypertension who lived at home with her husband developed kidney failure. After discussions with her nephrologist and husband, she commenced haemodialysis. Several years later, she ~~falls~~ fell and sustained a pelvic fracture, after which she ~~has~~ had a prolonged admission to a physical rehabilitation center. There, over several months, she ~~has~~ had significant ongoing pelvic pain, immobility, and cognitive deterioration, and she ~~is~~ was placed in a nursing home. The dialysis staff described seeing her deteriorating, often in pain and suffering. Her satellite dialysis unit ~~is~~ was isolated with limited opportunities to communicate these issues directly with the attending nephrologist, or the patient’s family. Moreover, the dialysis staff ~~feel~~ felt unsure and unsupported to have these conversations and therefore ~~are~~ were compelled to continue. They feel unable to initiate conversations about withdrawal from dialysis with the nephrologist, patient, or her family and compelled to continue.

Commented [A11]: Why? – clarified, due to social context and communication barriers perceived

Patients with CKD describe reliance on nephrology staff for end-of-life [discussions and](#) care [19]. However, nephrology providers are often ill-equipped to discuss end-of-life issues due to minimal training [20] and limited access to palliative care, which is rarely integrated into standard CKD and dialysis settings [21]. Staff providing dialysis can experience moral distress for patients who change clinical status due to acute illness, or, more insidiously, progressive frailty. These patients often have unmet palliative care needs, including uncontrolled symptoms and poorly defined advance care plans. Potential barriers of voicing concerns include hierarchical authority structures, traditional professional roles, limited interfaces between team members, financial incentives to continue dialysis and fear of being misunderstood. All could contribute to medical-cultural norms that disenfranchise staff or discourage discussion about withdrawal from dialysis. Moral distress can be compounded by regret for being complicit in such scenarios. [This may relate to balancing-a precarious balance-between- a desire](#) to speak up with [one's](#) professional role [described as](#); quietly doing ones' job as requested [15].

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Moral distress and power dynamics

- E. A 79-year-old woman with advanced CKD from diabetic nephropathy ~~has had~~ a large abdominal aortic aneurism. She ~~is was~~ high risk of fatal spontaneous aneurism rupture and ~~is was~~ offered urgent endovascular aneurism repair. Her post-operative course ~~is was~~ complicated with vasodilatory shock requiring vasopressors and anuric kidney failure. The nephrology service ~~is was~~ consulted to “start dialysis.” The nephrology trainee ~~discusses-discussed the~~ risks, benefits, and alternatives to dialysis with the patient’s husband, daughter, and son; and the significant chance she will remain dialysis-dependent. The patient’s family ~~is was~~ distraught as they say she would not want dialysis, especially if she would remain dialysis-dependent. When the trainee

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7 shares this information with the surgical ICU team, they ~~tell~~told him that he
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9 “overstepped a boundary” and it was “not his job to discuss goals of care.” The
10 surgical and nephrology attending discusseded directly with her family and dialysis is
11 initiated. The patient ~~experiences~~experienced several complications and after 2 weeks
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13 suffers a stroke and dies.
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17 Moral distress among physician trainees (residents and fellows) is described when feeling
18 obliged to provide treatments near end-of-life that could be futile [11]. In nephrology, this
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20 ~~commonly could occur~~occurs when dialysis initiation is compelled despite the doctor
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22 considering it being inappropriate, either due to patient preference or clinical deterioration
23 making dialysis likely to be futile. Moral distress among nephrology fellows can result from
24 perceptions of dissonance from supervising attendings, who may expect fellows to conform
25 to their practices. Although moral distress has not been studied among nephrology trainees,
26 negative emotional consequences fit under larger constellations of experiences described as
27 “burnout,” constituting depersonalization, emotional exhaustion, and cynicism [22].
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34 Despite limited professional experience, trainees in nephrology ~~see~~review high volumes of
35 patients, often occupying the “first-line” in complex decision-making discussions and
36 navigating expectations of patients, families, and other medical teams surrounding dialysis. In
37 some settings, dialysis rather than non-dialysis conservative care is the default treatment,
38 even in advanced age, cancer, heart failure, or severe debility [23]. Such expectations may be
39 entrenched and difficult for individuals, particularly trainees, to challenge.
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46 47 48 **Moral distress and the patient** 49

50 The implications of moral distress for patients, carepartners and communities also are
51 notable. Similar to healthcare providers, patients and carepartners also perceive constraints or
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external pressures and may be unable to act on their moral conscience. For example, a family member could experience moral distress when their loved one is requesting to stop dialysis if they perceive that cultural or religious contexts exist making this decision ~~is~~ unacceptable. A community with a member denied dialysis due to financial constraints may also perceive powerlessness and despair. This experience of moral distress has received limited attention in the literature.

Alleviating moral distress

While the above examples reveal the depth and complexity of moral distress in nephrology, the best approaches to alleviate moral distress remain uncertain. Avoidance of moral distress may deepen the demoralisation felt by an individual and is not the optimal strategy. Though multidimensional and potentially incomplete, the best approach spans several domains, including acknowledgement of moral distress, relying on evidence to guide difficult decisions, and leveraging available leadership and support to ~~help~~ approach scenarios that may induce moral distress. These multidimensional elements, described below, are conceptualised across domains of the micro level (the individual), meso level (the ~~facility~~ institution), and macro level (health services within and across countries) (Figure 1.)

Acknowledgement

Micro Level: Individual acknowledgement

The foundation of effective responses to moral distress is that an individual acknowledges that moral distress is present. Without acknowledgement, ~~or worse belittlement or dismissal~~

Commented [A13]: Clarify this clause -amended

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7 by peers or more senior staff, ~~the~~ moral distress may be compounded and those who voiced
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9 their concerns may be isolated and less ~~un~~likely to express their disquiet in the future.
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11 *Meso Level: Facilities fostering professional respect and courage*
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14 One challenge for health professional teams is how to respond to moral distress once
15 acknowledged. Certainly, for nephrologists, as decision-makers, once an action is perceived
16 as inappropriate, it becomes imperative to act. The nephrologist may be left questioning their
17 decision, asking ‘despite the evidence, what if I’m wrong?’ In medicine, few things are
18 absolutely certain. To reduce moral distress, nephrologists, like other doctors, must accept
19 some degree of clinical uncertainty. This process is best managed by ongoing discussions
20 within facilities that include a sense of realism and empathy.
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27 Echoing foundations of acknowledgement, professional respect is important in dealing with
28 moral distress. In nephrology, care teams provide the range of skills and professional services
29 required to provide holistic care. For example, dialysis nurses may spend more time with
30 dialysis patients and are therefore well-positioned to identify, support, and actively advocate
31 for patient’s needs [24], while the dietician or the nephrologist may be best positioned to
32 understand the potential clinical interventions, and the social worker may have the most
33 complete understanding of the cultural and social factors that will influence patient decisions.
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40 This highlights the interdisciplinary environment and contribution of different that each team
41 members’ ~~has important perspectives.~~ Accordingly, the interdisciplinary team can
42 collaborate to make comprehensive assessments of how patients are coping on dialysis in the
43 context of all aspects of their lives. Professional respect must be fostered within these units
44 to ensure all team members have their views heard.
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50 *Macro Level: Health systems acknowledging and anticipating sources of moral distress*
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Commented [A14]: Avoiding the phrase ‘nephrology units’ for a more general term that will be more widely applicable. - amended

Commented [A15]: I think you need to add something like this that highlights the interdisciplinary environment and that each team member has important perspectives. - added

An important factor in acknowledging moral distress is identifying and anticipating the most common sources. This results in earlier detection of opportunities for health care teams to discuss and debrief. Moral distress is at its core the perception of powerlessness to resolve inner turmoil (19) that arises from several common causes. These include uncertainty of leadership, resource limitations impacting patient care and adversarial end-of-life care scenarios [25, 26]. In nephrology, moral distress often stems from end-of-life care decisions [24] and treatment decisions influenced by non-clinical factors such as resource limitations [17]. Therefore, health care policies within and across countries need to focus responses on these areas as a priority. Further research identifying and acknowledging sources of moral distress are needed.

Evidence and Support

Micro Level: Individuals using evidence to enable discussion and transparency of decision making

Individuals can review current evidence underpinning ethically challenging scenarios to facilitate discussion, logical exposition and increased transparency around decision making. In turn, validation from colleagues or supervisors of concerns regarding the risks and burden of treatment decisions using data may provide opportunities to resolve moral distress. One example is decision-making when initiating dialysis. Current evidence suggests that dialysis may not provide survivorship advantage over a non-dialysis pathway for ESRD patients over 75 years with significant co-morbidities especially ischaemic heart disease [27, 28]. Paradoxically, this age group is the fastest growing cohort commencing dialysis in the United States [29].

Meso Level: Institutional support for shared decision making and infrastructure for optimal patient-centered care

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Responding to moral distress when navigating treatment decisions requires nephrology professionals to develop training and support to ensure the best treatment decision is made.

The existing guidance for approaching end-of-life decisions in advanced CKD focuses on pragmatic frameworks for shared decision making for older patients with CKD including essential areas discussed early and repeatedly with patients and families [30-32]. These include prognosis, patient priorities and goals, and how to align goals with delivered care.

Developing adequate infrastructure to provide legitimate, high quality, evidence-based care along the conservative management pathway is critical for easing moral distress. Without this treatment pathway, nephrologists may perceive that they are not able to provide sufficient care for their patients unless they offer dialysis. Ladin and colleagues found nephrologists who routinely discussed the option of conservative management with older patients felt less moral distress than those who did not [24]. The failure to raise conservative management as an option by clinicians was associated with beliefs that such management equalled “no care.”

Arguably, the provision of institutional support for an integrated kidney supportive care service would reduce disquiet felt in not providing dialysis, as well as ensuring that patients’ symptoms and psychological needs were addressed. As Ladin suggested, “Routinely discussing conservative management with patients older than 75 years may alleviate this [moral] distress, unify the approach among providers, and strengthen support among colleagues with common challenges”[24].

Macro Level: Health care policy focusing on ethical education and supports

Health care systems must include adequate access to ethical education in ethics and support so For clinicians can to reflect, communicate and act respondin to situations that may

~~prompt of moral ethical uncertainty distress. By developing ethical training in ethics as a priority, health systems must provide sufficient and pertinent education and support. The literature describes ethical educational intervention studies which provide a method to articulate, respond to, and reduce moral distress [33]. Healthcare education policies must ensure clinicians are adequately skilled to can improve support for clinicians to navigate, articulate and respond to in the ethically upsetting challenging situations which has shown to reduce that cause moral distress [33].~~

Leadership & Support

Micro Level: ~~Support~~ Leadership and communication opportunities for individuals

Individuals experiencing moral distress must show leadership amongst peers to voice moral distress. ~~This describes leadership and courage for a person at any level of the medical professional hierarchy to speak out or ask questions about behaviours or decisions that sit uncomfortably with their own core ethical beliefs. To do this shows leadership in the context of competing pressures such as conforming to group norms or professional expectations to perform one's role as requested. It is, therefore, vital that individuals in any role can communicate distress their concerns with colleagues or and senior staff members.~~

The staff member in turn must acknowledge the distress and have capacity to explore it thoroughly.

Meso Level: Leadership and advocacy in facilities

Experiences of moral distress are leadership issues. Leadership, in addition to practical and financial aspects, has pastoral dimensions, and clinical and educational leaders must create environments which allow acknowledgement of moral distress. Leaders have duties to be

Commented [A17]: This sentence is confusing.

Commented [DK18]: We have reworded this section for clarity and to minimise redundancy

Commented [A19]: 'Ethical' is an adjective here but should not be. Clarify. You more mean 'education in ethics' than 'ethical education'.

Commented [DK20]: We have added additional context to explain this concept

Commented [A21]: Clarify – who are the leaders in this section? What is meant by this? This is not described sufficiently to contrast with the 'Meso Level' section.

available to colleagues in distress and should dedicate themselves to advocate for strategies to identify and deal with distress. ~~Failure by senior staff to provide this leadership and advocacy~~ effectively buries distress that resurfaces as discontent and disillusionment. Indeed, unheard or ignored moral distress could indicate a limited ethical environment and deeper problems of communication, inadequate collaboration and perceived powerlessness [10].

Macro Level: Health care systems ~~review leadership~~ of resources and financing to ensure best care

Moral distress may be of a systems or communal nature. An example is countries where dialysis is extensively rationed. A response to moral distress may include collective actions by nephrology communities and policy advocacy to improve rather than neglect access to dialysis [34]. Policy makers must promote assistance and support for optimal and individualised kidney care. ~~Governments should fulfil responsibilities to provide adequate dialysis services and resource and structured conservative care to enable the best treatment for an individual and allow nephrologists to continue utilizing the best of their skills in kidney medicine.~~ Therefore, in responding to moral distress broadly, policy makers must lead changes in healthcare provision where ethical and funding clinical decisions are mal-aligned or conflicting. Health systems advocacy includes arguments based on health service adequacy, comparisons with other nations of similar economic status who provide greater dialysis access and an argument based on obligations of governments to realise the international human right to individualised and high quality healthcare.

Conclusion

Commented [A22]: Whose failure? Senior staff - amended

Commented [A23]: What if a government has to choose between influenza vaccination for 1000 people or dialysis for one? This is a very difficult policy space in many nations and the text here should acknowledge this. We think you could strike this sentence without losing anything.

Moral distress has two essential elements. First, the action transgresses one's core ethical framework. ~~S. Secondly, perceptions of constraints to act ethically. Secondly, moral distress is a perception of being constrained from taking the ethically appropriate action. -~~

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Nephrology is replete with clinical situations that may precipitate moral distress. The challenge for health professionals, nephrology practices, institutions and societies is how to acknowledge, manage, and lessen moral distress. Our ability to support and sustain ourselves and those around us depends on this response.

Article Information

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References

1. Thomas, T.A. and L.B. McCullough. *A philosophical taxonomy of ethically significant moral distress*. in *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*. 2014. Journal of Medicine and Philosophy Inc.
2. Epstein, E.G. and S. Delgado, *Understanding and addressing moral distress*. Online J Issues Nurs, 2010. **15**(3).
3. Epstein, E.G. and A.B. Hamric, *Moral distress, moral residue, and the crescendo effect*. The Journal of clinical ethics, 2009. **20**(4): p. 330.
4. Rn, D.S.H. and K.F. Rn, *Moral distress, advocacy and burnout: Theorising the relationships*. International Journal of Nursing Practice, 1999. **5**(1): p. 8-13.
5. Jameton, A., *Nursing practice: The ethical issues*. 1984.
6. Steiner, J.M., et al., *Moral Distress at the End of a Life: When Family and Clinicians Do Not Agree on Implantable Cardioverter-Defibrillator Deactivation*. Journal of pain and symptom management, 2018. **55**(2): p. 530-534.

7. Bader, C.S. and M.D. Herschkopf, *Trainee Moral Distress in Capacity Consultations for End-of-Life Care*. Psychosomatics, 2018.
8. Jameton, A., *Dilemmas of moral distress: moral responsibility and nursing practice*. AWHONN's clinical issues in perinatal and women's health nursing, 1993. **4**(4): p. 542-551.
9. Corley, M.C., et al., *Nurse moral distress and ethical work environment*. Nursing ethics, 2005. **12**(4): p. 381-390.
10. Schwenzer, K.J. and L. Wang, *Assessing moral distress in respiratory care practitioners*. Critical care medicine, 2006. **34**(12): p. 2967-2973.
11. Dzeng, E., et al., *Moral distress amongst American physician trainees regarding futile treatments at the end of life: a qualitative study*. Journal of general internal medicine, 2016. **31**(1): p. 93-99.
12. Wiggleton, C., et al., *Medical students' experiences of moral distress: development of a web-based survey*. Academic Medicine, 2010. **85**(1): p. 111-117.
13. Sporrang, S.K., A.T. Höglund, and B. Arnetz, *Measuring moral distress in pharmacy and clinical practice*. Nursing ethics, 2006. **13**(4): p. 416-427.
14. Weinberg, M., *Moral distress: A missing but relevant concept for ethics in social work*. Canadian Social Work Review/Revue canadienne de service social, 2009: p. 139-151.
15. Jameton, A., *A reflection on moral distress in nursing together with a current application of the concept*. Journal of bioethical inquiry, 2013. **10**(3): p. 297-308.
16. Moosa, M. and M. Kidd, *The dangers of rationing dialysis treatment: the dilemma facing a developing country*. Kidney international, 2006. **70**(6): p. 1107-1114.
17. Cervantes, L., et al., *Clinicians' Perspectives on Providing Emergency-Only Hemodialysis to Undocumented Immigrants: A Qualitative Study*. Ann Intern Med, 2018.
18. Wong, S.P., et al., *Care practices for patients with advanced kidney disease who forgo maintenance dialysis*. JAMA internal medicine, 2019. **179**(3): p. 305-313.
19. Davison, S.N., *End-of-life care preferences and needs: perceptions of patients with chronic kidney disease*. Clin J Am Soc Nephrol, 2010. **5**(2): p. 195-204.
20. Combs, S.A., et al., *Update on end-of-life care training during nephrology fellowship: a cross-sectional national survey of fellows*. American Journal of Kidney Diseases, 2015. **65**(2): p. 233-9.
21. Davison, S.N., *The ethics of end-of-life care for patients with ESRD*. Clinical Journal of the American society of nephrology, 2012. **7**(12): p. 2049-2057.
22. Dyrbye, L.N., et al., *Burnout among US medical students, residents, and early career physicians relative to the general US population*. Academic Medicine, 2014. **89**(3): p. 443-451.
23. Carson, R., *Deny dialysis or "D-NI" dialysis? The case for "do not initiate; do not ignore" orders*. Clinical Journal of the American Society of Nephrology, 2012. **7**(12): p. 1924-1926.
24. Ladin, K., et al., *Discussing conservative management with older patients with CKD: an interview study of nephrologists*. American Journal of Kidney Diseases, 2018. **71**(5): p. 627-635.
25. Crippen, D., *Moral distress in medicine: powerlessness by any other name*. Journal of critical care, 2016. **31**(1): p. 271-272.
26. Corley, M.C., *Moral distress of critical care nurses*. American Journal of Critical Care, 1995. **4**(4): p. 280-285.
27. Murtagh, F.E., et al., *Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5*. Nephrology Dialysis Transplantation, 2007. **22**(7): p. 1955-1962.
28. Brown, M.A., et al., *CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life*. Clinical Journal of the American Society of Nephrology, 2015. **10**(2): p. 260-268.

29. Saran, R., et al., *US renal data system 2017 annual data report: epidemiology of kidney disease in the United States*. American journal of kidney diseases: the official journal of the National Kidney Foundation, 2018. **71**(3 Suppl 1): p. A7.
30. Rosansky, S.J., et al., *Treatment decisions for older adults with advanced chronic kidney disease*. BMC Nephrol, 2017. **18**(1): p. 200.
31. Tamura, M.K., J.C. Tan, and A.M. O'hare, *Optimizing renal replacement therapy in older adults: a framework for making individualized decisions*. Kidney international, 2012. **82**(3): p. 261-269.
32. Association, R.P., *Shared decision-making in the appropriate initiation of and withdrawal from dialysis*. 2000: Renal Physicians Association.
33. Pauly, B.M., C. Varcoe, and J. Storch. *Framing the issues: moral distress in health care*. in *Hec Forum*. 2012. Springer.
34. Dirks, J. and N. Levin, *Dialysis rationing in South Africa: a global message*. Kidney international, 2006. **70**(6): p. 982-984.

Table 1: Clinical examples highlighting differences between ethical dilemmas and moral distress

	Example	Ethical Dilemma	Moral Distress
Working within systems with resource constraints	Dialysis is available for only one individual however two people require it urgently	Which patient has a greater need?	Access to dialysis is given to the person with insurance and not based on clinical need. Clinicians and patients feel unable to change the systems they work within regarding resource allocation
Dialysis treatment decision making	A patient with advanced dementia has developed ESRD and their family is asking to start dialysis	Dilemma associated with the cost to health care system, and associated risks versus benefits for the patient if dialysis is commenced	Dialysis is commenced as the patient is insured. A clinical decision is made influenced by external factors (eg. financial incentives) and the clinician feels unable to act otherwise. If clinicians experience the patient suffering as a result of the treatment decision, moral distress is amplified
Power dynamics	A patient on dialysis is clinically declining with an infected ischaemic foot wound foot ulcer , ischaemic limb and delirium. The surgeons have stated that they are unable to surgically improve her situation. As a result her prognosis is likely days to weeks. Her family want to continue all active treatments including antibiotics and dialysis and are threatening legal action if this is stopped	Issues raised of continuing likely “futile” treatments, and uncertainty whether the patients family are fully informed of her prognosis and are acting in the best interests of the patient	The attending continues all treatments as per the family wishes, with minimal discussion with the treating team, patient or family. Junior staff and dialysis staff perceive they are providing care that is prolonging suffering and they feel powerless, unsupported, unheard and compelled to continue

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*Note: all other comments are from the editors themselves.

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Figure 1. Strategies for addressing moral distress in Nephrology

	Acknowledgement	Evidence & Support	Leadership
Micro Level: Individuals, Clinicians, Patients and Caregivers	Reflection and acknowledgement that moral distress exists	Individuals using evidence to facilitate discussions around decision making	Individuals to show leadership and express moral distress when it occurs
Meso Level: Institutions and medical communities in a health care setting	Institutions fostering professional courage and respect	Improved evidence and support for shared decision making and conservative care	Senior staff obligation to understanding and respond to moral distress
Macro Level: Governments, societies and communities within and across countries	Acknowledging and anticipating common sources of moral distress	Resource priority to involve clinical ethical education and supports	Health systems and policy review of resources and financing to ensure best care

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	Acknowledgement	Evidence	Leadership & Support
Micro Level: Individuals, Clinicians, Patients and Caregivers	Reflection and acknowledgement that moral distress exists	Individuals using evidence to facilitate discussions around decision making	Individuals to show leadership and express moral distress when it occurs
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Figure 2: Actions for individuals and institutions to reduce moral distress*

- Schedule regular interprofessional “town hall” meetings to discuss challenging cases. Encourage submission of cases from all team members.
- Facilitate debriefing sessions after unexpected or distressing patient events in which all members of care team are expected to share their reflections. Triggers may include contentious interactions with patients/families, emotional family meetings, clinical decompensations (escalation of care, codes), and prolonged hospitalizations.
- Create an interdisciplinary ethics committee with members from physician, nursing, administrative, and legal backgrounds that can be called for consultation by ANY clinician experiencing moral distress
- Ensure confidential access for all clinicians to an employee assistance program for brief counselling services
- Create outlets for creative reflection and community building, including narrative medicine programs and arts nights
- Among trainees, emphasize education in ethics, communication skills, and pathways for clinician advocacy to drive healthcare reform
- Encourage explicit use of the term “moral distress” in all of the above activities

*In resource-limited settings, not all of these procedures will be possible.

Implementing even one may help detect, explore, and reduce moral distress.

Figure 2: Suggestions for institutions and individuals to address moral distress

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