

Developing the ethical framework of ESKD care: from practice to policy

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Short title: Ethics and end-stage kidney disease

Abstract

Ethical issues relating to end-stage kidney disease (ESKD) care are increasingly being discussed by clinicians and ethicists but are still infrequently considered at a policy level or in the education and training of healthcare professionals. In most lower income countries, access to kidney replacement therapies such as dialysis is not universal, leading to overt or implicit rationing of resources, and potential exclusion from care of those who are unable to sustain out-of-pocket payments. These circumstances create significant inequities in access to ESKD care within and between countries, and impose emotional and moral burdens on patients, families and healthcare workers involved in decision-making and provision of care. End-of-life decision-making in the context of ESKD care in all countries may also create ethical dilemmas for policy makers, professionals, patients and their families. This manuscript outlines several ethical implications of the complex challenges that arise in the management of ESKD care around the world. We argue that more work is required to develop the ethics of ESKD care, so as to provide ethical guidance in decision-making, and education and training for professionals that will support ethical practice in delivery of ESKD care. We briefly review steps that may be required to accomplish this goal, discussing potential barriers and strategies for success.

Key words: end-stage kidney disease; ESKD; dialysis; ethics

End-stage kidney disease (ESKD) and its management has significant clinical, social, and economic implications for patients, caregivers, and healthcare systems.^{1, 2} The burden of kidney disease is borne disproportionately by low- and middle-income countries (LMIC), where prevention, screening, and early detection are not commonly practiced, and access to treatment for ESKD is limited.^{3, 4} Growing awareness of the public health challenges within local, national, regional, and global contexts necessitates efforts to address these issues through better prevention and care of people living with chronic kidney disease (CKD) and ESKD. These efforts highlight ethical dilemmas arising from governmental, institutional, and organizational policy making, and similar ethical dilemmas occurring during the provision of care for health professionals, individuals, families, and communities.

Economics is not the only factor determining access to ESKD care however, as demonstrated in Latin America, where countries with lower income levels do provide universal access.⁵ Allocation of scarce economic and healthcare resources or the choice of treatment options for an individual with ESKD, requires consideration of norms and values peculiar to the clinical, social, and healthcare setting.

Acknowledgement of these will in turn assist in addressing potential conflicts relating to competing goals or differences in preferences, thereby promoting fairness in decision-making and clinical practice. An action plan to support the optimal delivery of ESKD care across a range of health care and income settings is outlined in Harris et al.⁶ In this article, we argue that more work must be done to develop the ethics of ESKD care, so as to provide ethical guidance in decision-making about ESKD issues. We briefly review the potential barriers and strategies to achieving this goal, with the aim of promoting better education and training of professionals with regards to the ethical delivery of ESKD care at various levels.

ESKD ethics has been a neglected field

Nephrology as a discipline has been influential in the development of clinical ethics, particularly since the introduction of chronic dialysis in the 1960s, given the high cost, life-sustaining nature of the intervention and its limited availability, which highlighted tensions between the ethical principles of

respect for autonomy, justice, beneficence, and non-maleficence.^{7, 8} Preliminary ethical guidance for policy and practice in ESKD patients in resource-limited settings that were identified by the Ethics Working Group are outlined in **Table 1**. Examples of ethical challenges relevant to daily management of ESKD in vulnerable populations are given in **Table 2**. Many ethical issues pertinent to end-of-life decision-making in other clinical contexts are also relevant to ESKD care. Patients with ESKD constitute a highly vulnerable population who cannot survive without access to care. Complex ethical challenges that extend beyond the individual are often particularly acute in this context. Ethical issues relating to ESKD are increasingly being discussed by clinicians and ethicists but are still infrequently considered at a policy level. Recent reports have identified important topics which merit consideration at the international level, in the context of local healthcare systems, and at the bedside.^{1, 2, 9} Several factors may have contributed to lack of formal attention being paid to ethical issues in ESKD care at the international level. These include a lack of systematic engagement with ethical aspects of nephrology by professional societies, and limited public and professional awareness of the ethical complexities of ESKD care. These factors also reflect the absence of significant multidisciplinary research in the field of ESKD ethics. In addition, controversy and often political sensitivity regarding rationing of health resources may discourage transparency and communication about resource allocation. Similarly, fear of creating tension within healthcare institutions, professional communities, and with industry partners may discourage efforts to address potential conflicts of interest in delivery of ESKD care.

ESKD may present significant ethical challenges

Challenges in achieving equity in ESKD care

One of the biggest challenges in ESKD care is meeting current and future global needs. At present, millions lack access to life sustaining treatment or treatment to relieve the physical and psychological burdens of ESKD.^{10, 11} Addressing the inequalities in access to care and health outcomes within and between populations requires paying careful ethical attention to the fair and transparent distribution of

available resources. Ethical questions relating to equitable access to care for ESKD, rationing of resources such as dialysis, and priority setting within healthcare systems more broadly, remain controversial but highly relevant in all countries, and especially in LMIC.^{2, 12, 13} In LMIC, inequitable access to care is driven largely by unavailability of care and/or inability to pay for treatment, which requires transparent ethical decision-making at the policy level.^{2, 14} In high-income countries (HIC) where access to modalities such as dialysis is mostly universal, concerns about equity of access to ESKD care also arise, e.g. when governments determine whether to extend access to ESKD services to migrant or asylum-seeker populations.^{7, 9, 15, 16} Ethical analysis is needed to determine the criteria, principles, and procedural frameworks that should guide resource allocation and delivery of care in each particular setting.

Ethical concerns relating to issues in resource allocation include disparities regarding clinical standards of care in resource-limited environments. For example, a reduction in the frequency or duration of dialysis for individuals may enable more patients to receive or afford treatment, but could negatively impact on clinical outcomes.^{2, 17} There is evidence, however, that some “compromises” in care, e.g. twice a week hemodialysis, may be acceptable in certain populations.¹⁸ The use of incremental dialysis to manage issues arising from insufficiency of resources requires deliberation, incorporating consideration of quality of life and physical status, feasibility, and ongoing consultation with stakeholders. Criteria used to determine eligibility, standards and priority for care, must be fair, openly communicated, clearly justified, and subject to regular review.^{2, 19, 20} Guidelines for priority setting and resource allocation are sorely lacking, and should be developed in a transparent manner that engages all stakeholders in decision-making. These guidelines must consider the objective analysis of cost-effectiveness, the need for financial risk protection, and the impact and severity of the disease burden.^{2, 13, 21-23}

Challenges in end-of-life decision-making for people with ESKD

In all countries, ethical dilemmas often arise during the end-of-life decision-making process for patients with ESKD, e.g. regarding the “futility” of dialysis, the relative risks and benefits of kidney

replacement therapy (KRT; dialysis or transplantation) for an individual, and the inevitable influence of various stakeholders as decision-makers, particularly when patients cannot make decisions for themselves. At times, families may be reluctant to consider dialysis if it is presumed to impose pain and suffering, or conversely, may insist on dialysis even if clinicians feel it may result in more harm than benefit. In many LMIC, lack of awareness of kidney disease and dialysis treatment within the community may lead to very late clinical presentation. These situations represent socially difficult situations where the patient may be too sick to benefit from attempted therapy, or may be too sick to survive the wait for family members to raise the out-of-pocket payment needed for treatment.^{4, 24} The impact of efforts to meet out-of-pocket payments for dialysis among poor families, and sociocultural factors that may influence individual and family decision-making about ESKD care, may also create ethical concerns and must be carefully considered.²⁵⁻²⁷ In the context of ESKD, lack of equitable access to adequate and sustainable dialysis leads inevitably to death, and not infrequently to financial impoverishment of the surviving family.²⁸ In addition, appropriate palliative care is often not available in many LMIC.^{4, 5, 29, 30} These circumstances are distressing not only for patients and families but also for healthcare workers. The importance of end-of-life care and advance care planning in the context of ESKD is well recognized, but lack of ethical guidance specific to the issues noted here may represent an additional barrier to effective care.³¹

Challenges in empowering people affected by ESKD to play a role in decision-making

Promoting autonomy is a core principle of bioethics,³² focused on respecting peoples' fundamental interest in being informed about and participating in decisions of importance to their lives. Promoting patient autonomy, which would empower people affected by ESKD to be involved in decisions that concern them, involves providing opportunities for choice and supporting people to act in accordance with their values, beliefs, and preferences, when possible. Worldwide, people tend to make choices in collaboration with others, including members of their broader family, religious and cultural groups. Many important life choices therefore impact not only individuals but also their families and communities, as well as those with whom they have personal, professional, and social relationships.

Increasing recognition that autonomy is a relational concept has led to the development of models of person-centered care and shared decision-making in clinical practice.³³

There are many practical barriers to promoting autonomy however, such as poor health literacy and language, as well as cultural barriers which may hinder inclusion of people in clinical and policy decision-making. Such barriers raise ethical concerns which relate to inclusion of individuals or groups in important decision-making about ESKD care. When patients cannot express their own wishes due to illness or incapacity, dilemmas may arise regarding who is the most appropriate alternative decision-maker, and how to ensure they are making decisions in the best interests of the patient. In some settings, cultural or religious norms dictate that patients make decisions in collaboration with specified persons, rather than in isolation.³⁴ Conflicts may arise if health care providers and patients, their families, or surrogate decision-makers disagree on the best course of action. In low-resource settings, dialysis may not be available, or a family may be unable to afford it. This may lead to ethical concerns on the part of care providers regarding whether to inform patients and their families about treatment modalities that may not be accessible to them.² Provision of too little information may result in families feeling cheated should they discover later that a therapy might have been accessible, or if they would have preferred to know of the options regardless of feasibility. On the other hand, those informed of treatment options may feel pressured to try to fund treatment or feel humiliated or guilty if they cannot afford it. Concerns regarding consequent financial harm to a patient and their family which may be considered disproportionate to the short-term potential benefits of providing dialysis if stopped soon once funds run out, may impact how and whether health care workers disclose information and may lead to moral distress.^{2, 35}

Challenges in identifying and managing potential conflicts of interest in ESKD care

The presence of potential or actual conflicts of interest in policy development or clinical practice raise ethical concerns about their potential influence on decision-making. Financial conflicts of interest are not uncommon in the setting of ESKD care given the high costs of KRT, and the complex health economies that sustain dialysis delivery.¹⁴ In many countries the bulk of ESKD care may be provided

through the private health sector, either because ESKD falls outside the scope of public health services or because capacity to provide ESKD care within the public health sector is absent or severely limited. Potentially harmful practices influenced by financial interests include service providers or insurers prioritizing stable or less complex patients who will require lower cost dialysis care; referring patients for care at particular centers where nephrologists have financial interests; referring patients for better reimbursed services such as hemodialysis rather than peritoneal dialysis; prioritizing dialysis over transplantation; recruiting patients in excess of a center's capacity to provide adequate care; or providing suboptimal quality of care for patients in order to save costs, such as compromising on quality and safety standards relating to infection control, water quality, or staffing ratios.

The financial interests of patients, their families, communities, health professionals, institutions, industry stakeholders, and governments may influence decision-making at all levels of the provision of ESKD care, and should be explicitly acknowledged and distinguished from clinical considerations and personal values and preferences. Governance mechanisms and ethical guidance are needed to ensure that potential conflicts of interest, especially on the side of health care providers, industry, and decision-makers are appropriately managed.

Developing the ethics of ESKD care through professional action

The ethical challenges briefly described above reflect only general areas of concern. Many specific and complex ethical issues may arise in the local context, requiring dedicated analysis to develop an ethical solution. Several actions that will assist in the global development of an ethical framework for ESKD care that supports ethical policy and practice and management of ethical issues locally and more broadly have been identified. These include development of “an international professional statement articulating core ethical principles and values to guide policy and practice in ESKD care” that would communicate the fundamental norms shared by the international community of health professionals working in ESKD.⁶ Like other globally oriented ethical position statements, such a

statement would aim to be influential in the development and application of ethical guidelines at national, regional, or local levels, informed by relevant community values, preferences, and health care system contexts. Additional actions include steps to increase the visibility of ethics in ESKD care and to empower those working in ESKD care to identify, manage, and develop solutions to ethical dilemmas and concerns within their contexts. Development of education and training tools and programs in ethics and of a strategic plan for interdisciplinary research to address the challenges of ESKD care that is inclusive of ethical concerns, will support these objectives. Finally, a key action must be to stimulate and support work on specific ethical issues that is aimed at providing ethical guidance for decision-making in ESKD care within policy and practice.

Implementing these actions will be difficult given the current neglect of nephrology as a clinical area of interest to ethicists, and health care professionals working in ESKD care may need to drive work in a disciplinary area in which they may have limited expertise. Furthermore, addressing the ethical challenges of ESKD care may seem a relatively low priority for health professionals, policy makers, and the public, given the substantial clinical and public health challenges relating to prevention and management of ESKD worldwide. However, it is clear that the clinical, social, economic, and public health challenges of ESKD are inextricable from ethical concerns. Exploring and addressing these challenges requires an interdisciplinary and collaborative approach if the clinical, social, and ethical objectives of ESKD care are to be met effectively.

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Tables

Table 1. Preliminary ethical guidance for policy and practice in ESKD patients in resource-limited settings

- Promote the physical, psychological, and social wellbeing of all persons affected by ESKD, including patients, their families and communities, and support healthcare professionals. This includes minimising harms wherever possible, striving to ensure that unavoidable harms are proportionate to the beneficial outcomes of policy or practice, and in general being advocates for ESKD patients.
- Promote social justice in ESKD care by promoting equity and fairness in access to care and resource allocation and upholding procedural justice through transparency and accountability in policy and practice.
- Promote the autonomy of ESKD patients by supporting their participation wherever possible in shared decision-making and informing them of available options for care, even if limited, but always respecting their values and culture.
- Recognize and address potential conflicts of interest in ESKD policy and practice.

ESKD, end-stage kidney disease

Table 2. Examples of common ethical challenges encountered in management of ESKD in vulnerable populations

	Autonomy	Beneficence	Non-maleficence	Justice
Principle	All relevant options must be presented, alongside physician recommendations, including appropriate KRT (if any) and supportive care	Options presented and provided should be focused on the patient's best interests	Goals of care should be carefully considered in order to avoid undue risk of harm	Resource allocation decisions should be made in a consistent, transparent, and equitable fashion
Examples of patient factors which may undermine one or more ethical principles	Age (elderly, children), gender, ability (multi-/co-morbidity), language barriers, culture, religious/spiritual beliefs, ethnicity, sexual orientation, geographical location, migrants, refugees, civilians in conflict or disaster situations, prisoners, socio-economic disadvantage (financial, health literacy)			
Strategies to increase awareness and maximize consideration of ethical principles	<ul style="list-style-type: none"> • Treatment decisions explained in understandable language, terms, without judgment, bias, or prejudice • Sufficient time to process information • Consider autonomy in context of social and cultural norms and values governing healthcare decision-making • Facilitate communication, with appropriate translators where needed 	<ul style="list-style-type: none"> • Consider the patient in the context of their family and community and respect their values, beliefs, and preferences when defining goals of care • Consider adaptations in care, e.g., use of tele-health, treatment times/frequency to accommodate work, travel, affordability where appropriate • Transplant listing (where appropriate) as soon as possible • Engage other practitioners, e.g., local GP or nurses, who can assist in delivery of care • Provide multidisciplinary care when possible • Consider supportive care for patients with advanced age, high symptom burden, etc. 	<ul style="list-style-type: none"> • Remain cognizant of additional barriers to care such as medication co-payments, food prices, work, schooling, socialization • Respect patient's primacy in evaluating potential burdens and outcomes of treatment • Avoid delays in end of life discussions to reduce avoidable burdens of treatment • Some interventions may represent an undue treatment burden, e.g., dialysis in elderly • Consider psychosocial support to navigate complex systems and improve comprehension and adherence if needed • Consider impact of treatment on family and community 	<ul style="list-style-type: none"> • Acknowledge and strive to address pervasive structural barriers to achieve equal opportunities of care • Implement priority setting where appropriate • Request additional support and cross sector collaboration to permit equitable access to the spectrum of available care options • Determine legalities around access to dialysis and transplantation for migrants and refugees. Advocacy may be required to achieve justice • Ensure local populations' needs are not unfairly compromised when meeting needs of migrants and refugees

ESKD, end-stage kidney disease; KRT, kidney replacement therapy (dialysis and/or transplantation); GP, general practitioner