Ethical challenges in nephrology: a call for action

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Abstract | The American Society of Nephrology, the European Renal Association–European Dialysis and Transplant Association and the International Society of Nephrology Joint Working Group on Ethical Issues in Nephrology have identified ten broad areas of ethical concern as priority challenges that require collaborative action. Here, we describe these challenges — equity in access to kidney failure care, avoiding futile dialysis, reducing dialysis costs, shared decision-making in kidney failure care, living donor risk evaluation and decision-making, priority setting in kidney disease prevention and care, the ethical implications of genetic kidney diseases, responsible advocacy for kidney health and management of conflicts of interest — with the aim of highlighting the need for ethical analysis of specific issues, as well as for the development of tools and training to support clinicians who treat patients with kidney disease in practising ethically and contributing to ethical policy-making.

Despite extensive research into factors that influence equity of access to nephrology care[1–6], and the publication of several studies on a wide range of ethical issues that nephrologists confront in their daily practice[7–29], limited clear and actionable guidance is available to clinicians on how to manage common and impactful ethical issues in nephrology. To address this problem, in 2018, the American Society of Nephrology (ASN), the European Renal Association–European Dialysis and Transplant Association (ERA-EDTA) and the International Society of Nephrology (ISN) formed a Joint Working Group on Ethical Issues in Nephrology. The group aims to highlight several important challenges of longstanding or emerging ethical concern for clinicians and to support the development of tools to guide ethical decision-making in clinical practice. Here, we address the first aim by describing ten challenges that have been identified by the Working Group as priorities for further ethical exploration and strive to motivate action on the second aim by explaining the potential value of ethical training and guidance tools to manage these issues.

The ten challenges comprise a range of interconnected issues that relate to improving global kidney health and the quality of life of people and communities affected by kidney disease (BOX 1). They were identified by the Working Group through a process of discussion and consensus (BOX 2). In this article, we focus on the role of health professionals in addressing these issues while acknowledging that engagement of other stakeholders, such as patients and policy-makers, and non-stakeholders such as ethicists and social scientists, in collaborative action, will be essential to support ethical policy and practice. Importantly, health professionals and other stakeholders face many additional challenges that are not discussed in this article, including problems, practices and policies that have important ethical implications, such as the costs of accessing screening and preventive care for kidney disease in the absence of universal health coverage, issues in paediatric decision-making and conflicts of interest in pharmaceutical prescribing.

Ethical issues in healthcare commonly align with universal concerns about decision-making, fairness, prevention of harm and promotion of the wellbeing of individuals and communities. Such issues require unique considerations in the local context, and responses must engage with local ethical and social priorities, values, preferences and frameworks for decision-making. Key factors, such as whether public funding is provided for dialysis, have a substantial impact on ethical decision-making and priorities for ethical action within countries. Clinical ethics is often case-specific, and general principles and ideas must be applied according to the specifics and dynamics of each situation.

By promoting and facilitating international discussion and collaboration, the global professional community may reach an understanding of fundamental ethical values that underpin clinical practice and ensure that ethical considerations inform international collaborative research on issues in clinical practice and health policy. Accordingly, this article is intended neither to provide in-depth ethical analysis of the selected challenges nor to outline specific practical strategies or recommendations for resolution of ethical issues in particular contexts. The aim is to inspire further work, not only on the issues selected for action by the Working Group but also on other issues that may reflect urgent challenges for stakeholders in particular regions, countries or communities.

Equity in access to kidney failure care

Equity in health refers to the absence of inequalities or differences that are avoidable, unnecessary and unfair[30]. Inequalities of potential concern in kidney failure care may include differences not only in access to existing services but also in clinician training, regional standards of existing facilities and resources, and degree of government support[31]. Inequities in access to integrated kidney failure care, including

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Box 1 | **Ethical challenges in nephrology**

- Achieving equity in access to integrated kidney failure care
- Setting priorities in kidney disease prevention and care
- Supporting shared decision-making about kidney failure care
- Avoiding futile or overly burdensome dialysis treatment
- Reducing the cost of dialysis care without compromising quality
- Preventing organ trafficking and ‘transplant tourism’
- Evaluating the risks and outcomes of living kidney donation
- Addressing the ethical implications of genetic kidney diseases
- Managing conflicts of interest in nephrology
- Advocating responsibly for kidney health

Each challenge should be considered in the context of other health and social priorities in individual countries and/or societies.

dialysis, transplantation, and comprehensive conservative and supportive care, are widespread both between and within countries[2,6,31]. Clinicians who are responsible for managing limited healthcare resources may experience ethical anxiety if they are uncertain how to approach decision-making because of a lack of guidance, training or experience and/or moral distress if resource constraints limit their ability to provide appropriate care to those in need[32,33].

Limited availability of kidney replacement therapies (KRTs) and access to available resources are primarily influenced by socioeconomic realities rather than clinical factors. However, in some cases, race, gender or citizenship status may determine or strongly influence access[4,5,34–36]. Criteria used to allocate health resources are often intended to promote greater utility of outcomes from the use of KRTs. Optimizing utility is usually interpreted as maximizing therapeutic gains (improvements in survival time and quality of life) from a given investment of resources. This approach may exacerbate health inequities by favouring patients who have less severe disease as a result of more privileged access to healthcare because treating patients who have a higher quality of life and/or are likely to live longer is often likely to have a greater therapeutic impact at a lower cost than treating patients who are sicker and/or likely to die sooner despite treatment (FIG. 1). Optimizing utility might therefore lead to a phenomenon known as ‘double jeopardy’[37], in which the least privileged patients are further disadvantaged in resource allocation.

Although efforts to increase the availability of resources and to address barriers to access are essential in reducing inequities and improving health outcomes for all[31], in the absence of sufficient resources, clinicians and policy-makers must strive to ensure that those that are available are allocated in such a way as to promote health equity. Determining frameworks for decision-making and criteria to guide allocation requires careful attention to the values and preferences of the populations among which resources will be allocated, and to the broader context of their social and healthcare systems and priorities[1,14,22].

Ethical issues in the allocation of organs for transplantation have received considerable attention[38], whereas equity of access to transplantation services has received far less scrutiny. The availability of a suitably matched kidney is essential to enable a patient with kidney failure to undergo transplantation, but many other factors underpin the inequities observed in rates of kidney transplantation at the local and international levels[6,34–36]. For example, when transplantation programmes are introduced, particularly in countries that lack universal health coverage, less affluent members of society are often excluded owing to financial barriers. This problem exists despite the fact that kidney transplantation and subsequent care are often less expensive than long-term dialysis. Financial barriers also exclude many patients from access to dialysis services. In 2010, >2 million people, mostly in low- and low-to-middle-income countries (LMICs), are estimated to have died as a result of lack of access to dialysis[2]. Even when the costs of dialysis care are substantially covered by insurance, related healthcare costs and social barriers to care may underlie a high rate of mortality in low-income populations[39].

Health professionals have an important role in promoting equity of access to dialysis and transplantation services as well as to conservative and palliative care services. In particular, they can assist in reducing barriers to access by promoting the development of transplantation and dialysis services in public rather than private facilities; ensuring the development of equitable and transparent frameworks for allocation of organs from deceased donors and for rationing of dialysis resources when necessary; supporting timely discussion of and referral for transplantation or conservative care where available and appropriate; supporting patients to discuss opportunities for living donation with potential donors; and facilitating a dialogue between patients and their families about conservative or palliative care as an alternative to dialysis.

Ethical issues may arise when a nephrologist makes a clinical judgement that a patient would not benefit sufficiently from transplantation or dialysis to justify use of a donated kidney or dialysis services or to justify the burdens that are associated with these interventions. Such burdens include the physical and psychological impact of transplantation or dialysis on patients, such as fatigue, depression, adverse effects of medications and complications of treatment, as well as requirements for lifestyle modification such as dietary restrictions and disruption to normal routines owing to time-consuming and expensive ongoing medical care[40]. Family and informal caregivers of patients receiving KRTs may also experience some of these or related burdens as they strive to support patients financially, psychologically and socially[41,42]. A patient’s prognosis in terms of survival following transplantation or commencement of dialysis might be weighed against the economic costs of KRTs and the potential physical, psychological and social costs for patients and their families[43,44]. For some patients, particularly those with comorbidities such as dementia that substantially reduce their quality of life and/or ability to cope with the demands of transplantation or dialysis, KRTs might be expected to offer limited, if any, benefits in terms of survival gains or relief of symptoms of kidney failure[40,43,45].

Clinical decision-making about suitability for KRTs may be subject to unrecognized social or cultural biases, for example, biases relating to patient age or ethnicity might influence the evaluation of risk factors for poor outcomes and underpin assumptions regarding the likelihood of non-adherence to treatment regimes in specific patient populations[34,46]. Decision-making may also be influenced by financial conflicts of interest, for example, if nephrologists or dialysis providers have a financial interest in retaining patients on dialysis rather than referring them for transplantation or conservative care[1,7,47,48]. These conflicts can occur when the design of healthcare systems and/or funding for dialysis and transplantation is such that nephrologists, nephrology units or hospitals can earn more by providing dialysis care to a patient than by providing post-transplant care. Such interests might also influence modality choice — for example, preference might be given to in-centre dialysis rather than home haemodialysis or peritoneal dialysis if a nephrologist has a financial interest in the centre or receives higher payments for providing in-centre care.

The development of practice guidelines, including ethical guidelines for allocation of resources when rationing is required, will support transparent, evidence-based decision-making regarding kidney failure care, help to reduce inequities in access to KRTs and reduce the risk of moral distress for physicians[32,49,50].

Priority setting for kidney care

Priority setting for research in kidney disease has been explored previously[51], but much work still needs to be done on priority setting for nephrology clinical practice[22]. Such prioritization is of particular concern for health policy-makers and health professionals in LMICs, where dialysis and/or transplantation programmes are being introduced that may entail long-term, potentially catastrophic costs to health systems and/or patients. Health authorities, policy-makers and the nephrology community must consider the implications of investing in kidney failure treatment, particularly high-cost KRTs such as haemodialysis, when such investment may occur at the expense of investment in treatment of other diseases that are greater public health priorities. In high-income countries, the introduction of high-cost, novel therapies may create similar dilemmas for policy-makers and/or insurance providers when deciding whether to subsidize these therapies, and for clinicians who support patients in choosing between treatment options.

Prevention of kidney disease is more cost-effective than the treatment of advanced kidney disease and its complications[52]. Nevertheless, investment in care of the relatively few patients who have kidney failure is often prioritized over prevention of the development and progression of chronic kidney disease in both high-income and lower-income countries[31,53]. Investments should be made in conservative and supportive care services for patients with chronic kidney disease and kidney failure as an alternative or complementary treatment to KRTs and also to provide care in settings where KRTs are not an option[31,54]. Where resources are limited, prioritizing prevention of kidney disease or conservative care may seem preferable to prioritizing KRTs for patients with kidney failure. This approach is likely to produce greater benefits overall for a larger number of people, satisfying utilitarian concerns that support a health-maximizing approach to resource allocation. Furthermore, investment in prevention is more likely than investment in KRTs to produce health benefits for the most disadvantaged populations, thus reducing inequities. However, investment in higher-cost services may offer additional benefits to communities, for example, by helping to prevent professional 'brain drain' and reducing medical travel abroad, thereby strengthening local health systems. On the other hand, such investment may promote development of a two-tier health system and create internal brain drain by attracting nephrologists to more expensive services that are more financially rewarding.

Maximizing utility should not be the only consideration in priority setting. Communities and individuals who are affected by priority decisions may have additional values and goals beyond utility gains, such as equity in opportunities for care, or may have preferences that include the provision of some opportunities for higher-cost care modalities. Furthermore, if investment in preventive care precludes provision of treatment for kidney failure, this restriction can create ethical dilemmas or distress for clinicians who encounter patients with kidney failure. Implementing policies that may result in denial of treatment to individuals is difficult for those who are trained to provide care as needed when a therapeutic relationship is established, especially if high-cost services such as haemodialysis are available to patients who can afford to pay for them.

Policy-makers and clinicians, together with patients and other stakeholders, may need to engage with a range of ethical dilemmas related to priority setting. Decisions regarding the prioritization of preventive, curative or palliative treatments or KRTs have implications for priority setting in workforce capacity building and training, as well as investment in clinical research and novel therapies. For example, training of nurses or allied healthcare fieldworkers may enable more effective provision of primary kidney care in lower-income countries[55].

Shared decision-making

Shared decision-making requires clinicians to respect patient autonomy (that is, their right to self-governance) by treating them as equals and supporting them to make voluntary and informed decisions about their care through a process of dialogue that explores all options for treatment, including conservative or supportive care (FIG. 2). Although definitions and implementation models vary[56], in many countries shared decision-making is now the standard conceptual approach to making clinical decisions. In nephrology, shared decision-making is particularly important when choosing KRTs or transitioning from dialysis to supportive care (FIG. 2). This approach is frequently recommended as a strategy to prevent conflicts in end-of-life care and to avoid futile treatment, particularly in the context of dialysis[57,58]. Shared decision-making is also a valuable tool to prevent coercion or manipulation of patients, which may result in unwanted treatment, for example, if nephrologists repeatedly question a patient's decision to decline KRTs[47].

Several potential barriers to use of shared decision-making exist. First, clinicians may be unfamiliar with this approach or may not be trained in its use. A 2015 study of American nephrology trainees highlighted gaps in self-reported preparedness to provide end-of-life care to

Box 2 | **Selection of the ethical challenges**

The American Society of Nephrology, the European Renal Association–European Dialysis and Transplant Association and the International Society of Nephrology (ASN-ERA-EDTA-ISN) Joint Working Group on Ethical Issues in Nephrology was convened by the leaderships of the three societies. The members include societal executive officers, nephrologists who have served on societal ethics committees and individuals with ethics expertise. This membership was not intended to provide a global demographic representation of nephrologists but rather to draw on the knowledge of society leaders regarding topical ethical issues that have been discussed informally within their societies over the past few years.

An initial review of the literature was performed to identify potential issues of interest pertaining to dialysis, transplantation and general nephrology. These issues were further considered in light of discussions held during an ISN summit on end-stage kidney disease (kidney failure) in Sharjah, United Arab Emirates, in March 2017 (REF.[31]). In May 2018, the working group discussed and refined the preliminary list of potential issues and selected a set of priority ethical challenges by consensus (BOX 1). These topics were chosen because they reflect concerns that are common to members of the three societies and are thus priorities for collaborative work. Two additional topics were added following feedback from reviewers on an earlier version of this manuscript. The chosen challenges comprise a range of interconnected issues that relate to improving global kidney health and the quality of life of people and communities affected by kidney disease.

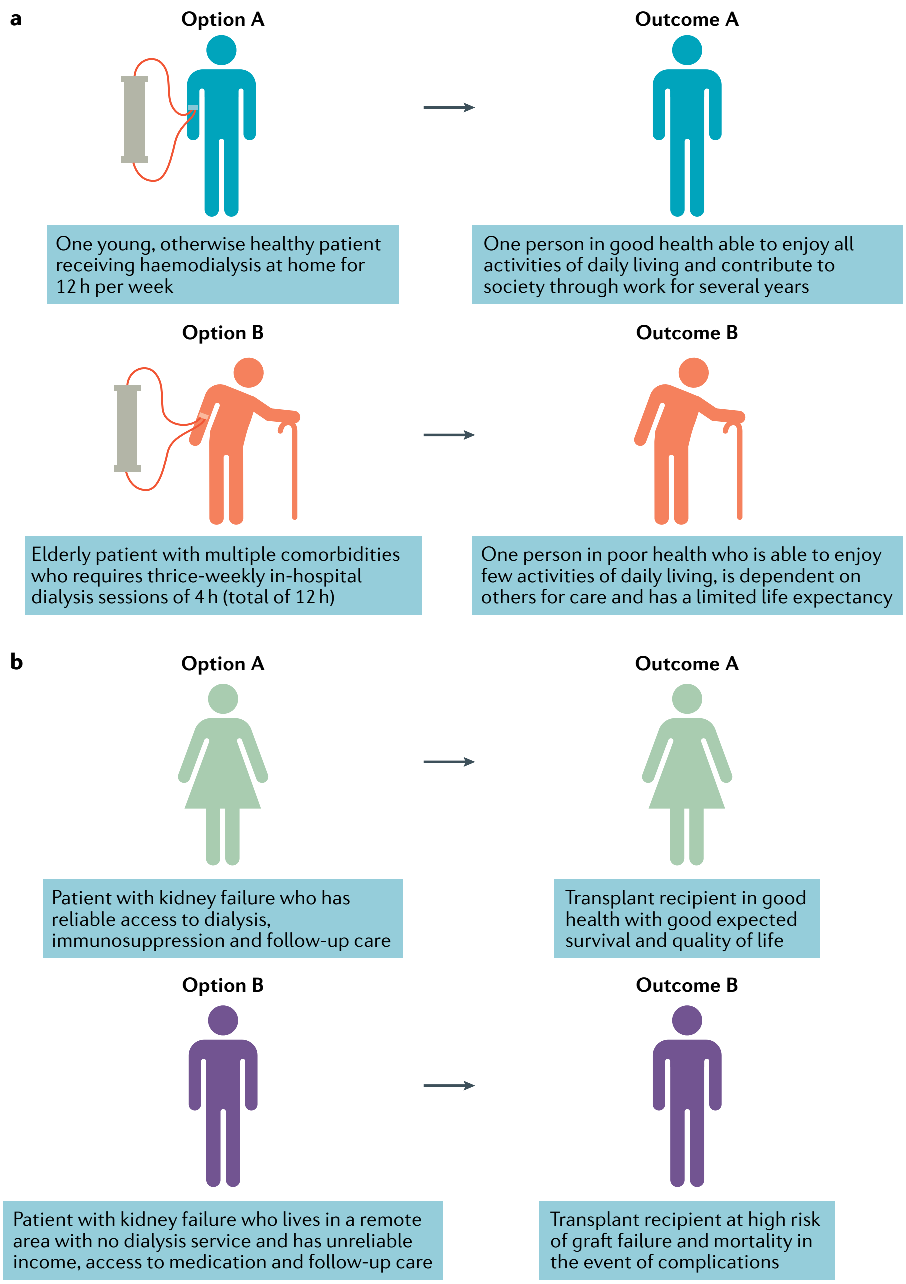

Fig. 1 | **Optimizing the utility of treatment outcomes in kidney failure can exacerbate health inequalities. a** | Allocation of haemodialysis tends to favour younger, healthier patients for whom treatment offers a better return on investment by optimizing health outcomes. Providing 12 h of in-hospital haemodialysis per week to an elderly patient with multiple comorbidities produces less utility (measured in terms of survival time, health status and quality of life) than providing 12 h of haemodialysis in the home for a young, otherwise healthy patient with kidney failure. Providing haemodialysis for the elderly patient is also likely to be the more costly option as they will require treatment for their comorbidities and might be more likely to experience complications. **b** | Health-maximizing approaches to the allocation of kidney transplant resources may favour patients who have more privileged access to healthcare as they are more likely to have good outcomes from transplantation (measured in terms of graft and patient survival) than patients who face barriers in accessing healthcare. In this case, the disadvantage experienced by patients who lack access to dialysis is particularly severe because if they are denied transplantation they will likely die from kidney failure.

patients, including lack of familiarity with existing guidelines for shared decision-making[59]. Providing training is important to support communication about treatment options and end-of-life decision-making in ways that are culturally appropriate and informed by the realities of the local healthcare system and social context[60–62].

Second, nephrologists may believe that discussions about end-of-life care, transplantation or dialysis modality choice are not a priority within the context of their professional role or should be referred or delegated to other healthcare professionals[60,61]. This barrier can be addressed through professional guidance to clarify responsibilities and by core speciality training aimed at developing the skills that are necessary to engage in such discussions effectively.

Third, some clinicians may believe that discussion of all treatment options for kidney failure may cause unjustifiable harm to some patients and their families; for example, if they are concerned that promoting living donation may expose potential donors to harm, if they believe that discussing transplantation when there is a low probability of a patient receiving a transplant may cause distress, or if they believe that the financial burdens of dialysis may be catastrophic for a patient and their family[22,63]. Perceived conflicts between physician duties of non-maleficence and respect for patient autonomy may lead to paternalistic practices with harmful consequences. Failure to disclose information to patients and their families about options for care (and their risks and benefits) that are within the reach of local possibilities shows a lack of respect for the autonomy of patients and their families, and disempowers them from advocating to address barriers to care. This failure may also lead to poorer decision-making, and undermine trust in therapeutic relationships, particularly as such information may be discovered through other means[64]. Health professionals working in environments in which treatment options are limited should carefully consider the implications of discussing or withholding information regarding treatment options that may be locally unavailable.

Avoiding futile dialysis

The avoidance of futile treatment — that is, treatment that will not achieve its goal or for which the disadvantages exceed the benefits in an individual patient — is a widely accepted principle in medicine. In practice, however, determining when an intervention is likely to be futile is ethically and clinically complex. Patients, their families and clinicians may disagree on the goals of treatment, the probability of achieving these goals, the clinical course of these goals, and the threshold for success at which futility may be defined. Conflicts may exist between the values, beliefs and preferences of clinicians versus those of patients and/or their families, particularly

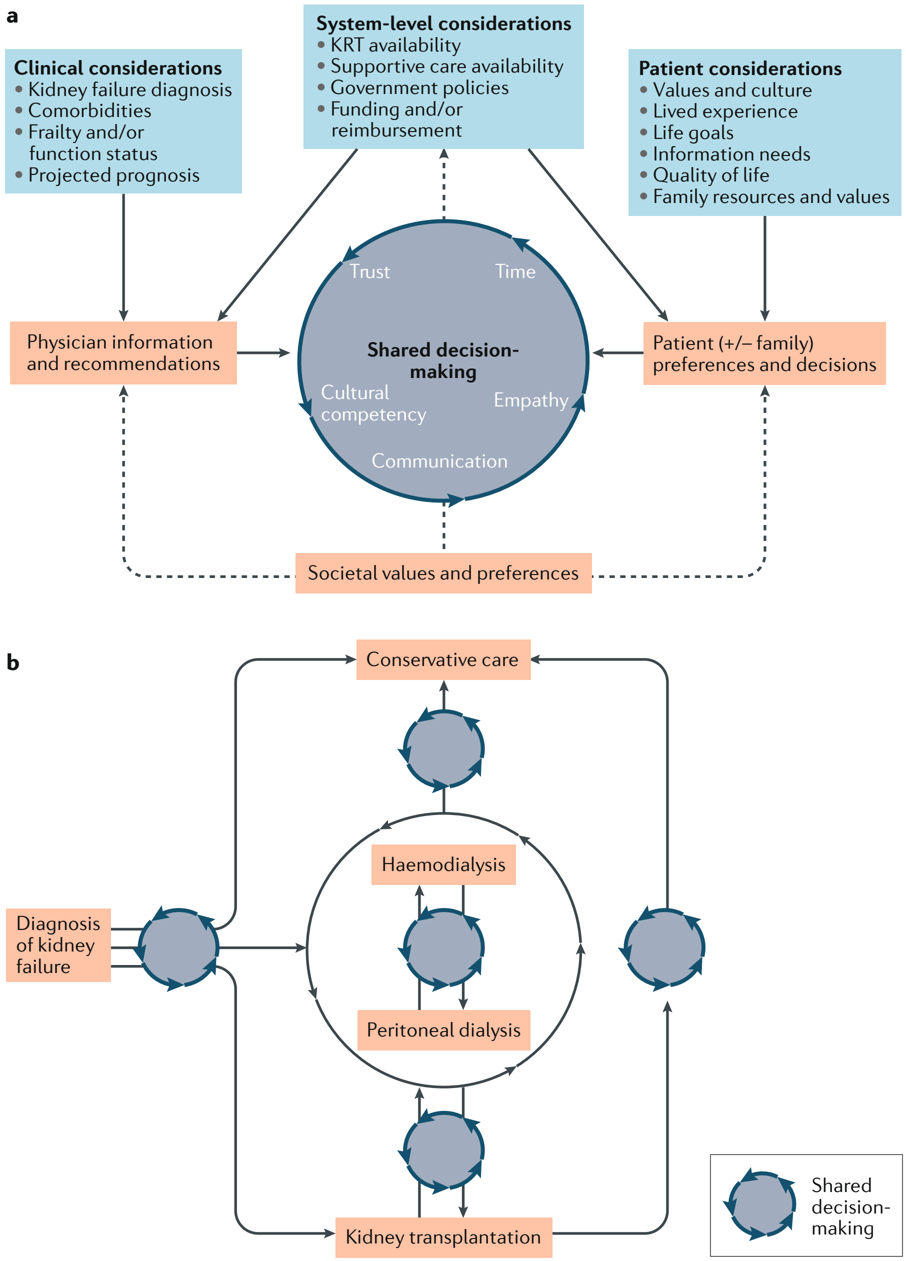

Fig. 2 | **Navigating pathways for treatment of kidney failure requires shared decision-making.** **a** | Considerations for shared decision-making in the context of kidney failure. **b** | Several decision-making moments may occur following a diagnosis of kidney failure. Patients may have a range of treatment options to select from, and may be required to re-evaluate their decisions in the light of resource constraints, treatment outcomes or opportunities for treatment, e.g. transplantation. Shared decision-making is a valuable process for patients, their families and physicians, even when treatment options may be limited. KRT, kidney replacement therapy.

within multicultural societies. Incorrect assumptions that a judgement of futility with regard to one intervention (such as dialysis) may preclude alternative treatments (such as comprehensive conservative care) or lead to the abandonment of care also complicate discussions of futility.

Although it may be straightforward to determine whether dialysis will be effective in performing specific biochemical clearance functions, such as partially correcting metabolic and homeostatic derangements in a patient with kidney failure, estimating their clinical prognosis and determining whether the initiation or continuation of dialysis will support their broader life goals may be more difficult[65]. For some patients, the potential benefits of dialysis may be outweighed by harms such as those that are associated with 'medicalization' of the end-of-life period, prolongation of a life that they judge to be not worth living or with a brief extension of life at a catastrophic financial cost to their family[40,66]. The provision of futile dialysis is not only harmful to patients but may also cause distress to their families and health professionals and impose a substantial burden on health systems[67].

More tools to support shared decision-making about dialysis, such as evidence-based decision-making tools[54,68] and guidelines developed by national or regional nephrology societies[62,69–71], as well as efforts to disseminate, facilitate and encourage the use of these tools, are needed. The use of such tools would support a more inclusive approach to shared decision-making in which health professionals, patients and their families can define the goals of care, engage with objective clinical evidence, formulate a shared understanding of the risks and benefits of the available treatment options (including a time-limited trial of dialysis) and have the ability to revoke or modify a previous decision[67]. Tools and training to support shared decision-making should also engage with relevant legal frameworks (such as those that determine legally authorized surrogate decision-makers for patients who lack decision-making capacity) and with tools to help facilitate resolution of conflict when fundamental disagreement exists between stakeholders as to the appropriate use of life-sustaining interventions. Knowledge of relevant legislative frameworks, for example, may help to ensure that physicians and surrogate decision-makers are confident in advocating for treatment or treatment cessation options that they judge to be ethically appropriate, without fear of litigation or criminal prosecution. The establishment of a systematic process for review and resolution of conflicts regarding the potential futility of an intervention, or other aspects of clinical decision-making, may be helpful in managing ethical disagreements[72].

Decision-making about the potential benefits and risks of treatment options for individual patients must be carefully distinguished from decision-making about resource allocation. Resource allocation guidelines should exclude the provision of futile treatments to avoid wasting healthcare resources. In cases where treatment is not considered to be futile, but rationing of relevant resources for treatment is unavoidable, patients may be denied access to a particular treatment if their need is not considered a priority according to ethically justified resource allocation criteria. The number of people in need of an intervention, and the potential benefits of treatment if it were available, should nevertheless be assessed and documented, and information regarding such cases should be reported to appropriate registries to inform and motivate efforts to improve the availability of resources.

Reducing the cost of dialysis

Efforts to reduce the costs of dialysis care are especially important in contexts where costs frequently preclude access. In Asia and Africa, for example, the majority of people with kidney failure cannot afford dialysis[2]. Health policy-makers and insurance providers may establish policies aimed at reducing the costs of care that may pose little threat to patient outcomes or quality of care, for example, by prioritizing peritoneal dialysis over haemodialysis[73]. However, some strategies that may reduce costs or enable more patients to access dialysis, such as reducing the duration and/or frequency of dialysis sessions, may have a negative impact on outcomes and thus pose ethical dilemmas for clinicians involved in decision-making. Conversely, efforts to improve the quality of care for some patients may reduce access for others. For example, in the context of limited availability, providing dialysis three times a week, as is standard in high-income countries, rather than twice a week, may reduce the number of patients who can access treatment[74].

Large, centrally located dialysis centres with consolidated expertise may provide better outcomes than smaller clinics[75,76]. In the context of peritoneal dialysis, such an advantage might in part be due to a positive association between provider support for this dialysis modality, patient volume and outcomes. Although smaller clinics might potentially be better able to tailor care to the needs of individual patients, healthcare providers in such clinics might collectively have less experience or expertise, for example, in managing particularly complex cases or rare complications. Smaller clinics might also have less ready access to broader healthcare expertise or specific healthcare resources, if clinic size is proportionate to that of local healthcare infrastructure or economies of scale preclude investment in the specific resources. However, the latter may provide greater access to care for patients living in remote areas.

The relationships, behaviours and decisions of multiple stakeholders may substantially influence the costs of resources required for the provision of dialysis and the financial returns that are available for individuals and institutions. Stakeholders and potential financial beneficiaries may include governments, healthcare providers and professionals, manufacturers of dialysis system components and drugs, and transport companies. For example, the cost of dialysis system components may be more readily controlled by health authorities when these are manufactured within the country, and the costs of providing dialysis care within a country may be partially offset by the benefits of the local dialysis economy, including taxes paid by service providers and consumers and the creation of local jobs. On the other hand, perverse incentives may encourage disproportionate expenditure on dialysis, for example, if nephrologists are paid high fees for providing dialysis care that may encourage over-servicing or discourage referral of patients for transplantation or conservative care. By contrast, in the context of a fixed payment for dialysis, there is a risk that cost-saving measures may compromise the quality of care in order to maximize profits, for example, by allotting the same budget to an increased patient volume so that the consultation time per patient is reduced.

Ethical analysis may assist clinicians, policy-makers and community stakeholders in managing potential conflicts of interest and making decisions that will promote better care and patient outcomes without creating or exacerbating inequities of access or quality of care. In addition, ethical guidance is needed to ensure that the fear of compromising quality of care does not lead to avoidance of care altogether. In some contexts, compromises may be necessary; clinical standards that are considered best practice and outcomes for dialysis care in some countries or communities may not be an appropriate measure of success in others, particularly when compared in the context of broader social and healthcare goals and standards. Moreover, standards that are deemed appropriate at one point in time might be later challenged based on new evidence. The nephrology community must strive to promote less expensive therapeutic options and to advocate for the research and development of affordable treatment modalities. Finally, ethical guidance may be needed to support decision-making when tensions arise between different ethical concerns. For example, if all patients want higher-quality care but only some are able to pay for such care, patient autonomy and concern for health equity are in tension. Furthermore, if informing patients of compromises in care may cause anxiety, distress or avoidance of care, then respect for autonomy and duties of beneficence and non-maleficence are in tension.

Organ trafficking

As many as 10% of kidney transplantations performed worldwide each year are estimated to involve organ trafficking, in which organs are treated as a saleable commodity, or transplant tourism, in which patients travel internationally to purchase a kidney in circumstances that involve organ trafficking or undermine national self-sufficiency in transplantation in the destination country[77]. These practices cause great harm to vulnerable people who are forced to sell their kidneys as well as to their families and communities[78–80], and also endanger the transplant recipients[81–83]. Furthermore, organ trafficking and transplant tourism have fuelled unethical practices, such as the execution of prisoners for organ procurement and sale in China, and the prioritization of wealthy foreign patients in the allocation of deceased donor organs[84,85].

Organ trafficking, particularly the procurement and use of organs from prisoners or individuals who are coerced into providing their organs[86], undermines trust in legitimate donation and transplantation programmes, and exacerbates inequities in donation and transplantation. Although ethical guidance is available at the level of broad principles established by the international community through the World Health Organization[87] and the Declaration of Istanbul Custodian Group[86,88], health professionals must contend with several complex ethical issues if they are to assist in preventing organ trafficking[89]. Ethical dilemmas may arise for nephrologists in managing patients who plan to travel abroad for an illegal transplant, who return from abroad after receiving a transplant that they suspect to have been trafficked or who they suspect to be involved in domestic organ trafficking[90–93]. These dilemmas often involve tensions between duties of care to patients and obligations to prevent harm to others. For example, refusal to facilitate travel abroad for transplantation when organ trafficking is suspected, for example, by declining to perform clinical investigations requested by the destination transplant centre, may delay or prevent patients from obtaining a transplant. Although such refusal is consistent with duties to prevent harm to the patient, given the clinical, financial and legal risks associated with travel for commercial transplantation, in many cases the overriding ethical justification may be the duty to prevent harm to others.

Ethical dilemmas also arise when reporting cases of suspected organ trafficking to inform actions against health professionals or others involved in transplant-related crimes may involve a breach of patient confidentiality[91,92]. More work is needed to support management of ethical issues relating to trafficking or tourism in the local context, for example, by establishing policy or legislation to govern and facilitate reporting of suspected cases of organ trafficking in a manner that protects patient privacy and vulnerable people who are forced to sell their kidneys, while enabling collection of data that may inform efforts to combat trafficking[91,92]. Health professionals may also assist in preventing organ trafficking and transplant tourism by providing education and counselling to patients who may be considering travelling abroad to purchase a kidney[86,89].

Risks of living kidney donation

A growing body of evidence regarding the long-term physical risks of living kidney donation within specific populations has enabled better risk assessment and in theory improved the quality of informed decision-making about living donation[94]. However, tools for evaluating and communicating risk to potential donors that have been developed for and informed by research in specific donor populations might be less relevant to other populations[25,95]. Emerging information about the psychosocial outcomes of donors and those who are declined as donors is also contributing to risk assessment and informed decision-making worldwide[94–96].

Living donors may risk financial injury as a result of taking unpaid leave to donate or if they experience a complication from the nephrectomy that impairs their ability to return to work. They may also incur costs relating to medical care required for the purpose of donation or long-term follow-up care after donation[97], as well as potential increases in premiums for health or life insurance or denial of insurance coverage[94]. Although infrequent, donors may experience psychosocial harm in the form of guilt, anxiety, depression or damage to relationships with transplant recipients or family members, for example, if the transplant is not successful or expectations relating to the post-transplantation relationship are not met[98,99]. Furthermore, prospective donors who are declined or decide not to proceed with donation may experience psychosocial harm in the form of anxiety, guilt or distress, particularly if their intended recipient is unable to obtain a transplant[100–102].

Clinicians and patients may experience difficulty in communicating and understanding the risks of donation, for example, when distinguishing between relative and absolute risks and when recognizing risks that are modifiable. Tools used to improve communication about risks in other healthcare fields such as oncology may help to support informed decision-making about donation[103]. Clinicians must contend with the ethical dilemma of determining when the risks are sufficiently great to justify refusing a willing donor[25,102]. Tensions may arise between respecting the autonomy of a prospective donor, supporting donation as a means of benefiting a person in need of transplantation and preventing avoidable harm to the donor. Such tensions may cause considerable ethical anxiety for clinicians, especially when the transplant candidate has limited chances of finding an alternative living donor or receiving a deceased donor kidney[104].

Despite the available evidence, tailoring risk management to individual prospective living donors remains a highly subjective process bound by considerable uncertainty, particularly in LMICs, in which access to allied health professionals and other resources to support the evaluation of psychosocial aspects of living donation may be limited. Nephrologists with responsibility for assessing prospective donors may lack expertise and experience in performing psychosocial evaluations and/or may have limited time to conduct such evaluations. It is particularly challenging to evaluate risks and consider these in the context of the potential benefits of successful transplantation to both the recipient and the donor, while respecting the important role of the donor in judging the proportionality of those risks and benefits[105]. More ethical guidance tools should be developed to assist in reducing ethical uncertainty and distress in contexts where clinical decision-making is not self-evident[106,107].

Genetic kidney diseases

Emerging information about the role of genetic and epigenetic factors in kidney disease[108] will expand the range of ethical issues confronting clinicians and patients. As is the case with genomics in medicine in general, increased use of genetic information in the investigation and management of kidney disease has potential benefits for patient autonomy and health, but also associated risks[108]. For example, use of genetic testing and genetic information may endanger patient privacy and confidentiality, and has the potential to cause harm to individuals, families and communities, for example, by increasing insurance premiums, creating social stigma or facilitating discrimination in employment. When a person is diagnosed with kidney disease, information about the aetiology of their condition may be relevant to their genetic relatives. Ethical issues may arise relating to obligations to disclose such information[109] and/or to protect individuals from unwanted information about their genetic risk of disease[110]. The ethical duties of the nephrologist in supporting disclosure may be unclear[111]. Issues may also arise in the context of decision-making about procreation by an affected individual or couple[112]. Greater understanding of the genetic and epigenetic factors that influence kidney disease is also having an impact on treatment decision-making[113] and risk assessment, including for potential living kidney donors who wish to donate to a genetic relative[114].

In LMICs, unavailability of tools for genetic diagnosis and/or counselling may undermine the quality of care available for patients and increase inequities in access to care. The inability to identify a genetic cause of disease may lead to inappropriate treatment and the waste of scarce resources that could have been avoided with improved diagnosis of disease aetiology. To ensure that patients have access to appropriate care and are supported to make informed decisions about their care and the management of their genetic information, nephrologists require training and continuing education in this field, not only from a clinical and scientific perspective but also with regard to the ethical implications of genetic kidney diseases. Nephrologists should also advocate on behalf of patients for access to resources such as genetic testing and counselling services.

Managing conflicts of interest

As noted above, conflicts of interest on the part of various stakeholders, including health professionals and patient and advocacy organizations, may influence decision-making and undermine care and equity of access to care in the context of kidney disease. In particular, individual and organizational financial interests may influence the goals and priorities of patients, clinicians, healthcare providers and policy-makers and require careful management. The financial impact of kidney disease on societies, healthcare systems, patients and their families is substantial[115–117]. Reluctance to explicitly

Box 3 | Working Group on Ethical issues in Nephrology action plan

Form working groups to address the ten challenges
Convene multidisciplinary, multinational working groups, including patient stakeholders, who will be responsible for ongoing work on each challenge. This work will involve the exploration of issues and the development of tools, including educational resources.

Develop a global multidisciplinary network and resource bank in nephrology ethics
Establish an e-mail list and website to facilitate networking, for example, by providing a source of information to assist people and organizations to find collaborators with relevant expertise, and to communicate information about opportunities for collaboration. The website will host a curated set of relevant resources including ethical analyses of specific issues, guidelines and educational tools.

Establish dedicated streams for nephrology ethics at society conferences
Dedicated space for discussion of ethical topics will be established in society conference programmes to give greater prominence to existing work on ethics in kidney health, highlight the importance of ethics to health professionals and facilitate the development of collaborations to investigate current and emerging ethical issues in nephrology.

acknowledge and engage with financial interests when setting goals of care or policy not only undermines transparency but may also have harmful consequences. For example, disproportionate investment in dialysis without comparable development of transplantation services and preventive kidney health programmes may hamper efforts to implement sustainable solutions to the problem of kidney disease.

Conflicts of interest can also have an impact on the development of clinical practice guidelines, for example, if financial interests on the part of companies sponsoring guideline development or individuals contributing to guideline development influence judgements regarding clinical best practice[118–120]. Strategies to prevent such an impact include mandatory requirements for the declaration of potential conflicts, recusal of individuals from involvement in decision-making when a conflict of interest exists and mandatory disclosure of unavoidable, potential or perceived conflicts of interest when guidelines are published.

Management of conflicts of interest requires clear processes and policies for use in particular contexts and specific attention to broader contextual factors that may underpin such interests or make their avoidance difficult. For example, the financial interests of physicians may be embedded in the structure of health payment systems such that their influence on clinical decision-making is readily overlooked.

Further work on the ethical implications of conflicts of interest in nephrology is needed, particularly with respect to determining situations in which such conflicts should preclude participation by individuals or organizations in decision-making[118]. Popular management strategies such as disclosure of conflicts are of limited efficacy[120], and do not address the inherent ethical concerns regarding the impact of bias in decision-making, clinical judgement or scientific analysis. In addition, exploration of potential conflicts of interest within families who need to make decisions regarding treatment of kidney failure, as well as management strategies to address these conflicts, would be helpful. For example, clinicians may face difficulty when caring for prospective living related donors who may be emotionally and/or financially dependent on prospective transplant recipients and with families for whom decisions about initiation or cessation of dialysis may have significant financial consequences.

Responsible advocacy

Advocacy by health professionals in collaboration with patient organizations and individuals is vital to promote awareness and understanding of kidney health. In some contexts, advocacy may also be influential in gaining funding for research or care services from government, industry or philanthropic sources. Several ethical issues may arise in the context of advocacy efforts for kidney health. To date, no research has explored ethical issues of advocacy in this specific context.

First, growing awareness exists of ethical concerns regarding conflicts of interest in relationships between industry, professional medical societies and patient advocacy organizations[121,122]. The need to foster and maintain positive relationships with potential funding sources that are necessary to support vital research, training or community engagement activities may discourage kidney health advocates from speaking out on specific topics or issues in which funders may have a vested interest.

Second, factors that may influence the efficacy of advocacy efforts and fundraising appeals may also influence decision-making by organizations regarding which diseases, populations or therapies to prioritize for advocacy, potentially creating or sustaining inequities in kidney care. Such factors may include a lack of evidence or knowledge regarding the impact of particular diseases in specific populations, costs of care, stigma, political bias and perceived severity of need for care in a particular population[123–125].

Third, physicians, patient organizations and other groups may intentionally or unintentionally exploit vulnerable patients or communities in advocacy efforts. Use of personal narratives is an established method of soliciting public donations to charities and promoting kidney donation[126,127]. Problematic practices in kidney health advocacy may include soliciting financial donations from wealthy patients and asking patients, their families or communities to publicly share stories of personal tragedy or disease that may be helpful in raising awareness or attracting funding[128,129]. The representation of individuals or communities in advocacy materials may expose them to stigmatization or violate their privacy if they feel unable to decline. Ensuring that therapeutic relationships are not exploited in this way and protecting individuals who may be unable to choose autonomously whether to participate in advocacy efforts, such as children, is essential. Establishing ethical guidelines to govern advocacy efforts would help to address such concerns, for example, by setting standards for transparency, consent and management of conflicts of interest.

Conclusions and a call to action

Each of the challenges described above comprises a range of complex issues that may have specific implications in the context of particular populations or healthcare systems. Each of these complex issues requires in-depth analysis by expert groups in order to understand the factors that underpin them and the ethical concerns that they may present in specific contexts. Collaborative action by nephrology communities, including stakeholders such as policy-makers and patients, is needed to develop tools, training modules and other resources to guide decision-making and support ethical practice. The ASN-ERA-EDTA-ISN Joint Working Group on Ethical Issues in Nephrology will encourage members of the three societies and partner organizations to initiate in-depth discussions about these issues with the aims of supporting the development of tools to guide ethical decision-making in clinical practice, adapting these tools to local contexts, building capacity amongst nephrologists to recognize and respond to ethical challenges, and making routine the application of these tools and principles to health policy, clinical practice and research (BOX 3).

We call on health professionals, members of patient communities, policy-makers, ethicists, health economists and social scientists to take action in exploring and addressing ethical issues in nephrology that are of concern in their local context. Although ethical considerations in research and clinical decision-making are often noted in passing, we believe that giving a more prominent place to engagement with ethical issues is necessary. The ASN-ERA-EDTA-ISN Joint Working Group is eager to establish a sustainable programme of work that will enable regular review of issues and resources that may require updating in the light of emerging evidence or contextual changes that influence the manifestation and management of ethical issues. The societies are also committed to working in collaboration with other regional and national societies of nephrology, in order to draw on the wealth of global expertise and experience, and to ensure that the needs, values and preferences of the global community inform the development of a global bank of resources supporting ethical practice in kidney health.

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