Ethical issues in dialysis therapy

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For International Society of Nephrology Ethical Dialysis Task Force

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SUMMARY

Treatment of end-stage kidney disease is a major economic challenge and public health concern internationally. Decision-making related to renal replacement therapy poses several practical and ethical dilemmas of global relevance for patients, clinicians and policy makers. They include promoting patients' best interests, increasing access to dialysis while maintaining procedural and distributive justice, minimizing the influence of financial incentives and conflicts of interests, ensuring quality of care in service delivery and access to non-dialytic supportive care when needed, minimizing the financial burden on patients and healthcare system, and protecting the interests of vulnerable groups during crisis situations. These issues have received comparatively little attention, and limited ethical analysis and guidance is available to decision-makers. This paper provides an overview of the major ethical issues currently related to dialysis provision across the world, identifying priorities for further investigation and management, and presents preliminary recommendations to guide current practice and policy.

INTRODUCTION

Renal replacement therapy (RRT), the life-saving treatment for end-stage kidney disease (ESKD), is provided by chronic dialysis or by kidney transplantation. Transplantation extends life, provides better quality of life and is more cost effective compared to dialysis[1,2]. However, many patients are not suitable candidates for transplantation, and the availability of transplantation is limited by the persisting global shortage of donor kidneys, and in some countries, lack of infrastructure. Dialysis is, by comparison, more readily available. The prevalence of patients receiving dialysis has risen throughout high-income countries (HIC), to an estimated 1176 per million of population (pmp)[3]. In contrast, a large proportion of ESKD patients in low and lower middle-income countries (LLMIC) lack access to dialysis. An estimated 2.28 million patients died in 2010 because of dialysis non-availability or unaffordability, almost all in the LLMIC.[3]

In addressing the economically and socially costly burdens of advanced kidney disease, health policy makers and professionals confront many ethical issues. These are particularly challenging in the context of ESKD and RRT, where clinical and policy decisions may be a matter of life and death. The *International Society of Nephrology* (ISN) convened an Ethical Dialysis Task Force to examine this subject. In this paper, we briefly explore several aspects of dialysis provision, which raise ethical concerns of global relevance. While ethical issues require elaboration in the context of specific healthcare systems and patient populations, we provide here some general recommendations for practice wherever dialysis services are available.

FINANCING OF DIALYSIS

The global market for dialysis was valued at over US$75 billion in 2011.[4] The costs of providing dialysis, and the costs incurred by dialysis patients vary between and within countries,[5,6] as the following examples illustrate. In the United States 468,000 people received dialysis in 2013, with the total Medicare spending of US$30.9 billion, representing 7.1% of total healthcare expenditure.[7] In Thailand, an estimated 12,000 people received dialysis at a cost of US$76 million, or 2% of national healthcare expenditure.[8] In the United States, the average annual cost of providing dialysis to a patient was US$22,000,[9] compared

with approximately US$3,200 in India.[10] These costs usually cover only dialysis therapy, not ancillary expenses such as medications, transportation, etc. Factors that influence the absolute costs include the local economy for healthcare products and services, the funding model for dialysis, and the healthcare system. These factors determine if, and how much, the patients are required to pay upfront for dialysis.[11] In India, for example, the cost of a haemodialysis session to patients in different facilities may vary from US$10 to 50.[10]

Financial interests and service delivery

The costs of dialysis provision are influenced by system-level factors that incentivize policies or practices that may financially benefit industry, institutions and health professionals. In a pay-for-performance system, prioritization of less complex patients likely to require fewer interventions ('cherry picking') will positively affect performance metrics and result in financial benefits to clinicians or facilities.[12] Nephrologists may also have financial interests in referring patients for dialysis at particular centres; recommending specific RRT modalities (for example, centre hemodialysis instead of home based therapies);[13] and avoiding referral for transplantation for fear of loss of revenue or, conversely, prematurely referring for financial gain.

Such conflicts of interest may result in higher costs for patients or healthcare systems, or in compromised clinical care. Lowering costs is important because financial barriers are the primary cause of lack of access to dialysis, and because many patients suffer serious financial harm as a result of dialysis treatment. Out of pocket payment for dialysis often constitutes catastrophic health expenditure for patients and their families.[14] Physicians and dialysis centres may also compromise patient care in order to reduce costs, increase profits, or provide care to more patients. In some regions, for example, dialysis units exhibit wide variations in the quality of workforce, adherence to standard operating protocols, dialyzer reuse practices, and standards for water treatment, vascular access, and infection control.[10,15] Dialysis session duration and frequency may be reduced to accommodate extra patients, and documentation of patient care is often suboptimal.[15]

In addition to the costs of dialysis itself, management of comorbidities and complications of dialysis also requires substantial investment. From the perspective of policy makers, the costs of providing dialysis may be most easily reduced by investment in prevention and management of CKD, [5] and improving access to transplantation.[1] However, financial considerations and pressure from interest groups may encourage policy makers and physicians to prioritize investment in dialysis at the expense of other services, or discourage investment in development of cheaper dialysis machines and consumables. While dialysis is justified as a 'life support service', the lack of investment into adequate prevention and delay of progression results in ongoing growth of the dialysis population and costs attributable to ESKD.[16]

CLINICAL CARE AND DECISION-MAKING

Decision-making about dialysis may create ethical dilemmas regarding autonomy, beneficence, and nonmaleficence. For example, how can we enable patients or their surrogate decision-makers to make informed and voluntary decisions regarding treatment of ESKD? Or, when is dialysis in the best interests of the patient?

Consistent with the principles of beneficence and non-maleficence, dialysis should only be provided when it is clinically appropriate. Provision of futile interventions imposes costs, undermining efforts to provide necessary healthcare to all patients. However, where the financial costs are not an immediate concern for patients or physicians, initiation or continuation of dialysis may be considered the default option or clinical norm for patients with ESKD. A review of qualitative research suggests that patients may experience a lack of choice about dialysis treatment.[17] Factors that may undermine the quality of patients' decision-making include inadequate information about options, timing and expected benefits of dialysis, insufficient time for decision-making, resource constraints, influence of peers and family, and reluctance to deviate from the *status quo*.[17] Patients at the extremes of age, those with multiple co-morbidities, those who present with an acute diagnosis of ESKD, the poorly educated, and those from socioculturally marginalized groups may experience additional barriers to effective decision-making. Other barriers include cognitive

impairment or immaturity, language difficulties, and lack of data concerning outcomes of treatment for particular groups.[18]

Clinical decision-making

Physicians have a responsibility to provide competent patients or their surrogate decision-makers with sufficient information about treatment options, which they can evaluate in the light of their own values and preferences. In a patient with ESKD, this means explanation of all available RRT options: the benefits, burdens and consequences of dialysis; differences between various forms of dialysis – HD or PD, home or in-centre dialysis – and alternatives, such as kidney transplantation and non-dialytic conservative care.[19] Discussion of benefits and burdens should be evidence-based as much as possible, with data interpreted in the context of the individual patient's qualitative treatment goals.

Discussions should include the potential physical, psychological, and socioeconomic consequences of specific choices, and patients and their families should be given time to reflect on their options and to ask questions, especially before making critical decisions such as initiation or withdrawal of dialysis. The initial decision to commence or decline dialysis should be open to review at a later date.[20]

Professionals involved in dialysis decision-making should be wary of their own potential biases, and factors that may undermine or compromise their clinical objectivity, such as lack of familiarity with dialysis in a specific patient population or personal financial interests in particular treatment modalities. Training in communication and ethical decision-making related to provision of end-of-life care may assist physicians to support effective decision-making and to manage issues that may arise, for example, when dealing with surrogate decision-makers and conflicts with advance care directives. Guidelines to support shared decision-making and advance care planning may be useful, particularly in the context of ESKD.[21] Education programs for patients and surrogate decision-makers are also valuable in improving health literacy and empowering autonomous decision-making about RRT.

Care when RRT is not appropriate or available

Many individuals with ESKD will receive conservative care rather than RRT – either because limited resources make dialysis unavailable, or because dialysis is not initiated or is withdrawn in the patient's best interests. Irrespective of the reasons, these patients should receive the best available care. Furthermore, patients receiving dialysis may also benefit from access to supportive care or hospice services.[22] As patients approach the end of life, provision of palliative care becomes essential.

Conservative and palliative care programs are emerging as key strategies for management of ESKD where access to RRT is limited. However, many countries with inadequate dialysis services also lack adequate palliative care services. Where such care is unavailable, patients dying from ESKD experience significant suffering, which places enormous psychosocial burdens on caregivers, families, and communities.[22] Where palliative care services are available, patients may not receive a timely referral if nephrologists are unfamiliar with those services or do not see provision of palliative care as part of their professional responsibilities. Emerging evidence suggests that nephrologists and health systems are becoming increasingly aware of the importance of being able to provide end-of-life care to their patients.[23]

DISTRIBUTING DIALYSIS RESOURCES

Even when dialysis is in the best interests of patients with ESKD, resource constraints may limit the ability of health service providers to treat all patients. When making decisions about funding, governmental authorities must consider the broader health needs present and resources available within the population. If access to dialysis is solely determined by the ability of patients to fund their own treatment, authorities should, at the very least, assist in reducing the costs of dialysis so that financial inequities in access are reduced. When governments are able to fund dialysis for at least some patients, respect for justice requires that efforts are made to promote equity in access to the available resources.

To achieve equity in treatment where inequalities of access are unavoidable, fair and transparent criteria and procedures governing access must be established.

Although the goals, values and principles that should govern access to dialysis in a particular society may vary, a number of considerations will be common to all societies seeking to promote health equity.

Procedural justice requires that decisions about access policies should be made by legitimate authorities, who are accountable to those affected by the decisions. Such decision-making should be transparent, informed by relevant evidence and ethical principles, and consistent in the application of principles or rules. Procedures should be established to engage stakeholders and experts in decision-making and to provide opportunities for appeal and revision of individual decisions. Key stakeholders and experts include patients with ESKD and clinicians working in nephrology: integration of their perspectives will help to ensure validity and feasibility of policies.

Distributive justice requires the development of frameworks to guide allocation of limited resources, for example, guidelines to determine eligibility for access to dialysis, or access to funding for dialysis. Groups determining eligibility criteria may face several potentially conflicting goals, such as the maximization of utility, commonly interpreted as maximizing the number of quality adjusted life years (QALYs) gained by providing treatment to particular individuals or groups, versus maximization of equality of opportunity, for example by providing everyone with a period of free dialysis, in order to give them time to pursue a potential kidney transplant or to find their own funding for dialysis. A third goal might be to promote equality in life span. In pursuit of this goal, younger patients would usually be prioritized for dialysis, to compensate for the greater reduction in their life expectancy compared to that of older patients in the absence of treatment.

Criteria may be applied in order to promote particular goals of allocation policy. Some criteria that are commonly associated with unfair discrimination, such as age and economic status, may be justifiably included in policies where they objectively influence legitimate considerations such as risks and benefits of treatment. However, care should be taken to ensure these are not simply used as proxies for evidence-based evaluation of the likely outcomes of treatment in

particular populations. Further, modifiable factors that may influence utility calculations, for example, economic status where capacity to fund treatment of comorbidities might influence the value of dialysis, should be used with caution and only as a temporary measure while efforts are made to address underlying socioeconomic inequities.

Access criteria and policy must be informed by an understanding of broader access issues relating to prevention and management of CKD, supportive care, care of comorbidities and complications, and general healthcare services. In South Africa, for example, access to dialysis is conditional on a commitment by patients that they will accept a transplant.[24] This policy has, in theory at least, the advantage of providing more patients with the opportunity for dialysis by effectively reducing the number of long-term dialysis patients (depending on the availability of renal transplants). However, patients who face barriers to transplantation, such as adolescents considered at high risk of noncompliance with immunosuppression, or those unable to afford immunosuppression, may be denied the opportunity for dialysis (Muller E, personal communication). This represents a case of double jeopardy, in which the access policy may further disadvantage those already suffering from disadvantage.[25]

Even in countries where access to dialysis is unrestricted, systemic factors may undermine equity, particularly in minorities and socioeconomically disadvantaged groups.[26,27] Even when they receive dialysis, it may be in lower quality facilities. For example, despite living closer to higher quality dialysis units than their white counterparts, African-Americans are less likely to obtain care in such units.[26] This may be due to more segregated social networks with limited information about options for care, preferential referral to lower quality facilities, or non-acceptance in higher quality centres that engage in 'cherry-picking'. In emerging countries, patients may be unable to make the high out of pocket payment charged by better quality facilities.

All access policies that involve rationing should be regularly reviewed in the light of evidence concerning their outcomes, as guidelines sometimes produce outcomes that conflict with their intended goals. For example, the policy

regarding dialysis funding in Texas aimed to minimize governmental costs of providing care to undocumented migrants while prioritizing the saving of lives, by offering only emergency dialysis. This instead resulted in more costly care and poorer patient outcomes.[28]

Managing resources in crisis situations

Health systems may confront specific crises that place unexpected pressures on delivery of dialysis services and may necessitate revisions to policies for resource allocation, at least temporarily. Environmental disasters, such as earthquakes, may not only reduce the availability of existing resources by destroying dialysis units or preventing transport of essential products such as dialysis fluid, but also produce a surge in demand, as a result of acute kidney injury. In addition, public health disasters, such as the 2015 Ebola epidemic, may result in increased demand while complicating the delivery of dialysis services by exposing dialysis personnel to risk of infection.[29] Finally, economic or social crises such as the surge of refugees reaching Western Europe in 2015, may also result in demand for dialysis services beyond a country's capacity to provide them. Societies that may have well-established policies of providing care to all, including refugees, for example, may be unable to do so as a result of reduced service availability, or due to overwhelming financial burdens.

Existing policies must be evaluated in the light of resource constraints and demand for services during crises: existing values and principles must be reapplied, not necessarily reevaluated. The outcomes may fall short of the desired goal, but the resultant inequalities should be just. In responding to crises, or in planning for potential crisis management, policy makers may draw on pre-existing crisis management plans such as those developed in anticipation of influenza pandemics.[30]

CONCLUSIONS

Despite substantial international differences among healthcare systems and public health priorities, the core ethical values and principles of health service provision are common to all societies. Grounded in the human right to health, they include the promotion of equity, provision of best possible care, the

prevention of harm, and the engagement of patients and their families when making important decisions about their own care. Application of these values and principles in practice will have different results in different healthcare systems, according to the practical realities, cultural preferences, and relative value accorded to particular health-related outcomes. Nevertheless, international collaboration is needed to investigate areas of ethical concern in dialysis provision, and to establish common ethical frameworks, clinical guidelines, and educational resources that may be adapted to the local context. Collaboration improves efficiency, and ensures more robust examination of ethical issues from diverse perspectives.

Panels 1-3 highlight preliminary recommendations for ethical governance, policy, and practice, which must be further explored in dedicated projects. ISN will elaborate a context-specific plan of action for research, policy development, resource growth and program implementation in ethical dialysis and integrated ESKD care.

Providing care for patients with ESKD is practically and ethically complicated for physicians and policy makers across the world. Together with patient organizations, nephrologists have an important responsibility to advocate on behalf of patients with ESKD in the promotion of care and ethical practice and policy, and to engage with policy-makers. Collaboration with other health professionals and researchers addressing similar ethical and practical concerns in other fields of healthcare will facilitate advances in development of resources for clinicians, for example, guidelines for shared decision-making and management of conflicts of interest; and for policy makers, for example, analysis of resource allocation issues.

Ensuring equitable access to RRT and best practice care for ESKD for all patients presents major ethical, practical, and economic challenges for healthcare systems. Challenges – some of which may be more pressing in emerging economies – include increasing access to dialysis; helping patients and families to make the best decisions about management of ESKD; ensuring that patients receive high quality chronic dialysis based on current standards accepted

worldwide, and have access to high quality end-of-life care when required; ensuring the cost of dialysis does not unduly burden the healthcare system or patients; and minimizing the impact of financial conflicts of interests on decision-making in policy and practice. Other important challenges that the global community faces include the provision of dialysis to specific populations during periods of crisis. The global nephrology community must work to address these issues, in collaboration with other health professionals, health authorities, patients and their families.

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PANEL 1: ETHICAL PRINCIPLES AND GOALS FOR HEALTH AUTHORITIES AND DIALYSIS CARE PROVIDERS

- Individuals with ESKD should have access to the best available care in RRT and supportive and end-of-life care when required[21].
- Health professionals and policy makers should strive to reduce the costs of dialysis, using simple, safe, and affordable modalities without compromising the quality of care provided to patients (for details, see http://www.dialysisprize.org/).
- Commercial conflicts of interests on the part of policy makers and health service providers, including nephrologists, should be routinely disclosed to the public and patients.
- Where rationing of dialysis resources is necessary and unavoidable, access to dialysis should be equitable.
- Physicians have an obligation to provide information about risks and benefits of dialysis and to support patients or their surrogate decision-makers in qualitative evaluation of treatment options.
- Decisions about initiation or withdrawal of dialysis should not be considered irrevocable, however decision-makers should be informed of the potential limitation of future options that may be the consequence of initial decisions.
- Policies and guidelines governing access to dialysis should strive to:
    - Avoid futile treatment.
    - Assure a minimum expected benefit threshold, below which the burdens of initiating or continuing dialysis are considered disproportionate and hence unacceptable (within the sociocultural context).
    - Promote equality of opportunity.
    - Maximise utility gains from the available resources.
    - Exclude criteria that are not morally justifiable with respect to allocation decisions such as race, gender, religion or social status.
    - Ensure transparency of policies and processes.

415

PANEL 2: PRACTICAL RECOMMENDATIONS REGARDING DIALYSIS FOR HEALTH AUTHORITIES*

- Efforts to reduce the costs of providing dialysis to those with ESKD should occur in conjunction with more cost-effective efforts to prevent development of ESKD and to manage ESKD within a population. For example, health systems should establish programs of kidney disease prevention and health promotion in conjunction with RRT programs.
- Minimum standards of quality and safety should be established for all dialysis units and regulations introduced where necessary to ensure standards are maintained.
- Audit systems should be designed to facilitate and encourage documentation of patient care and transparent reporting of costs and outcomes of care, in order to provide an evidence base for decision-making and objective evaluation of performance.
- Regulatory safeguards should be implemented where necessary to prevent undue commercial influences on clinical decision-making.
- Locally appropriate policies or guidelines governing access to dialysis should be developed and transparently implemented in accordance with principles of procedural and distributive justice.

**National or regional issues may influence specifics of these recommendations, but we recommend transparency in clinical practice.*

416

PANEL 3: PRACTICE RECOMMENDATIONS FOR HEALTH PROFESSIONALS INVOLVED IN DIALYSIS CARE

- Nephrologists and renal care nurses should collaborate with other health professionals, social scientists, and ethicists, in the investigation of specific ethical issues at the local, regional, or international level.
- Priorities for research may include: assessment of the impact of costs on clinical decision-making in different countries; investigation of burdens of care in special populations such as infants, and those with complex comorbidities. Such research may inform development of evidence-based communication tools and allocation policies respectively.
- Professional societies and medical councils should ensure that healthcare professionals working with patients with ESKD are familiar with their responsibilities for patient care, including their obligations to provide care to those who might be perceived to pose risks to care providers, e.g. from infectious disease, and to provide or refer patients to palliative care services.
- Supportive care should be made part of ESKD management plans, and appropriate facilities should be developed. Examples
- Guidelines for clinical decision-making, specifically with regards to withdrawal of dialysis; “Do Not Resuscitate” orders; and time-limited trials of dialysis; should be developed. Where guidelines exist and have been implemented, sharing of best practices and outcomes across jurisdictions is essential.
- Nephrologists should refer patients to available services when they are unable to provide such care.
- Nephrologists should receive education about shared decision-making, advance care planning, and end-of-life counselling and communication about end-of-life care.
- Dialysis providers should be trained in clinical decision-making conversations, and develop multidisciplinary teams in collaboration with providers of other treatment options such as transplantation or supportive care.
- Dialysis units should institute a process of “second conversation”, which will prepare the patient for future decline and serve as an optimal time for advance care planning if the conservative care pathway is chosen.