

EDITORIAL

Key ethical challenges in providing dialysis in low-resource settings — A view from the trenches

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Introduction

Maintenance dialysis is life-sustaining but poorly accessible in low- and middle-income countries (LMICs). There are not enough functional dialysis centres in the public sector, and in the private sector, dialysis is prohibitively expensive. This results in the need for (de facto) rationing of public sector dialysis beds or catastrophic out-of-pocket expenditure. Death occurs in the majority of patients from lower socio-economic backgrounds because dialysis cannot be initiated or must be discontinued [1]. Kidney transplantation is even more inaccessible than dialysis due to inadequate transplant centres and high costs [2]. Conservative care is a continuation of medical care without dialysis that focuses on symptom control and end-of-life care. In high-income countries (HICs), conservative care is usually chosen by elderly, frail kidney failure patients or those with multiple serious comorbidities [3]. In LMICs, conservative care is the only treatment option when dialysis or kidney transplant is inaccessible. In high-resource settings, shared decision making by patients and nephrologists regarding dialysis versus conservative care would ideally occur before kidney failure has occurred. Unfortunately, in LMICs, chronic kidney disease (CKD) is often diagnosed late when the patient becomes severely ill from advanced symptoms of kidney failure, requiring emergency initiation of dialysis [4]. Kidney failure in children is usually caused by congenital diseases that present differently from those in adults. Late diagnosis and urgent-start dialysis is typical [5]. Paediatric dialysis is only provided in a few specialised centres in LMICs. Thus, parents/caregivers must shoulder the burden of medical caregiving and its associated costs. In these difficult circumstances, physicians face several ethical challenges in their struggle to provide the best possible care despite resource limitations [6].

In this issue, two papers highlight some of the ethical challenges of providing dialysis in low-resource settings — the high costs of dialysis, even when it is provided “free of charge” to the patient, and the role of affordability in decision-making.

1. Beneficence versus non-maleficence

Lanewala and Shekhani highlight the catastrophic indirect costs of “free” paediatric haemodialysis in 52 families of children with kidney failure in a tertiary dialysis and transplant centre in Pakistan [7]. Despite the free dialysis, caregivers were faced with a heavy financial burden, due to geographic inaccessibility. Caregivers had to pay out of pocket for travel to the dialysis centre or had to leave their homes to move closer to the hospital. The indirect healthcare costs included lost income by daily wage earning caregivers and job loss. Almost all patients discontinued schooling permanently. The education of siblings also suffered as they had to take on family caregiving duties. The financial burden resulted in impoverishment and mental stress — 37% of caregivers reported symptoms of anxiety and depression and even suicidal ideation [7].

In these circumstances, nephrologists do not have the luxury of advising dialysis thinking only of the best interests of the affected child, even if this is typical of paediatric bioethical decision-making in HICs. What is in the best interest of the child may put an entire family at risk of financial ruin. A child with kidney failure would benefit medically from dialysis, but by advising dialysis, are physicians causing harm to their families?

In addition to highlighting the ethical dilemmas encountered, the authors have generated important data about the true costs of “free” dialysis. This adds to the literature on catastrophic healthcare expenditure incurred during public sector dialysis that is

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available for adult patients [8]. In the absence of a national registry, these single centre studies provide key information to spur advocacy efforts.

2. Patient autonomy

Kendal and Bhatt discuss their concerns that patient autonomy around dialysis initiation may be limited when they are poor and unable to afford dialysis costs [9]. The authors argue that this could occur in two situations: First, when nephrologists may paternalistically withhold information about dialysis or transplant, believing that patients may be distressed at their inability to afford these treatments. Second, when physicians may choose the opposite strategy of presenting all medical information impartially, including treatments that are clearly inaccessible. The best interests of patients are not served, because they are burdened with making a choice between life and death without any guidance.

Kendal and Bhatt propose a gradual disclosure of information in increasing order of costs as a solution to avoid this dilemma. They suggest that the diagnosis be disclosed first, followed by (cheaper) conservative care options and lastly, only if the patient desires to hear more, should dialysis, its costs and associated “financial toxicity” be disclosed [9].

In our opinion, this strategy of offering conservative care first applies when the decision to continue with conservative care only is truly a “choice to be made” by the patient, such as those who are frail or with severe comorbidities where survival and quality of life may not be improved by initiation of dialysis. Ending the discussion if the patient does not want to hear more about the complications or cost of dialysis is then fair, and would indeed result in reduced distress to the patient. However, in reality, except for this minority, dialysis is life-saving and prolongs survival when compared to conservative care. Thus, the relevant ethical dilemmas surrounding kidney failure treatment in low-resource settings extend beyond those discussed by Kendal and Bhatt, cause significant distress to patients and physicians and must be addressed urgently to improve outcomes.

The first is the circumstances of kidney disease diagnosis. Unlike their counterparts in high-resource settings, people with risk factors for kidney disease in LMICs are denied timely screening, diagnosis and preventative care. They have a higher burden of disease, greater morbidity and mortality based on socio-demographic and economic factors. Such a difference in outcomes based on where one is born, lives and works is unfair, and violates the principle of social justice [10, 11].

The second is the lack of universally accessible dialysis in LMICs. The stark reality is that there is insufficient public money to support maintenance dialysis for all those who need it. In countries with limited universal healthcare coverage, dialysis must be rationed and physicians must determine who lives and who dies (from lack of dialysis). From the patients’ perspective, rationing limits their ability to make an autonomous choice, even when the treatment itself is “free” or “available”. The criteria for determining eligibility might unfairly discriminate against older patients, those with poor resources to travel for care and those with comorbidities [12]. In settings where patients have no option but to pay out of pocket for dialysis, we believe that the injustice of “enforced” conservative care instead of dialysis, due to their inability to pay, is greater than any theoretical scenario where treatment options might be paternalistically withheld.

The ethical challenges of medical decision-making in low-resource settings

A nephrologists’ practice is fraught with challenges beyond the order in which treatment costs should be disclosed. There is a moral duty to disclose the diagnosis and all available treatments — the benefits versus the burdens of each, including the costs. They are required to actively participate in decision-making with patients and caregivers who are frequently overwhelmed with the diagnosis of kidney failure and its implications. This dependence on the physician places an unfair burden of responsibility on taking the right decision [13]. Are physicians obligated to take social factors of the patient and family into consideration during medical decision-making? In situations where rationing is required, denying patients life-saving dialysis is associated with significant moral distress, especially when ethical rationing policies do not exist [14]. Also, morally distressing is the frequent underdialysis and non-adherence to therapy that LMIC nephrologists must accept when patients face financial hardship, lowering their own high standards of care.

Ethical solutions

Respect for autonomy, beneficence and non-maleficence are key to ethical medical decision-making for individual patients. However, to improve outcomes of kidney failure as an important non-communicable disease, policy-makers in LMICs must address distributive justice [15].

Ideally, all those who require and wish to accept dialysis as a treatment should be able to access it. Forgoing or withholding dialysis because of the inability to pay reflects inequitable access to care which the global community has a moral responsibility to rectify and cannot be justified behind a veil of “respect for autonomy”.

Free or subsidised dialysis addresses the lack of affordability, but is only one part of the solution. Improving awareness of kidney

disease to allow early diagnosis, increasing the availability of well-staffed kidney care centres, providing social support to caregivers and offering holistic conservative care where appropriate are key areas for improving equitable access to care [16].

To advocate for such policy changes, the nephrology community must generate outcome data of patients with CKD through the creation of national registries [17]. Armed with these facts, all stakeholders (patients, physicians and the community) must issue a call for action by policy makers to equitably provide universal healthcare coverage for all levels of kidney disease care, provide support to cover the “hidden” costs of dialysis and to create ethical and transparent rationing guidelines [18, 19]

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