

## COMMENT

## Financial toxicity and dialysis: Autonomy and truth-telling in resource-limited settings

EVIE KENDAL, ROHIN BHATT

**Abstract**

*From an ethical perspective, resource limitations provide a challenge for healthcare providers. Handling disclosure of the financial details of treatment options in a way that empowers patients, even in the face of extreme poverty, requires careful consideration of the personal preferences and motivations of each patient. This article will consider the high costs of dialysis for patients experiencing extreme poverty in light of various ethical principles, including informed consent and truth-telling. It will conclude that a graduated method of disclosing the physical and financial burdens of each treatment option is the best way forward, particularly for healthcare workers engaged in resource-limited settings.*

**Keywords:** end-stage kidney disease; end-stage renal disease; dialysis; autonomy; informed consent; truth-telling; cost of treatment.

**Introduction**

Chronic kidney disease entails progressive loss of kidney function and has an estimated global prevalence of 13.4% [1]. A proportion of these cases — currently estimated to be between five and ten million people worldwide — progress to end-stage kidney disease, a condition characterised by water retention, fatigue, uraemia, electrolyte and pH imbalances, and renal anaemia, among other symptoms [1, 2, 3]. Progression to end-stage kidney disease indicates a need for renal replacement therapies, such as dialysis. However, referral patterns have been shown to be inconsistent depending on patient age, co-morbidities, and perceived ability to pay for treatment [3, 4, 5]. The latter point has been a particularly common concern in low- and middle-income countries.

Dialysis is one of the most expensive life-sustaining interventions commonly used around the world, and nations at all income levels are struggling to keep up with growing demand [6]. Jha notes that interventions for end-stage kidney disease account for 2-6% of healthcare expenditure in developed countries, despite these patients only accounting for 0.1-0.2% of the total population, citing examples such as the USA (6.3% of the Medicare budget), Japan (4.1% of the total health budget) and the UK (1.3% of all health spending) [7]. Bradshaw et al also note a large increase in dialysis demand in “resource-constrained” settings, noting similar rates of growth in dialysis populations in South Africa, Mexico, Brazil, the Philippines, China and India [6]. In their 2019 study of the effectiveness of India’s Pradhan Mantri National Dialysis Programme (PMNDP) for defraying the costs of dialysis for low-income families, these authors found 91% of their 835 participants on maintenance haemodialysis experienced catastrophic health expenditure, even after the relevant subsidies [6]. Catastrophic health expenditure was defined in this study as monthly out-of-pocket medical expenses exceeding 40% of non-food household expenditure. Distress financing, defined as “borrowing from family/friends, selling possessions, or taking out loans to fund dialysis care” was reported in 77% of participants, who were subsidised by a mix of charity and/or government support, and private patients recruited from various dialysis clinics in Kerala, India [6]. These authors compare this “near universal” financial distress related to maintenance dialysis to other costly diagnoses for patients in India, with cancer and cardiovascular events requiring hospitalisation leading half the affected households to experience catastrophic health expenditure [6]. While prior to the PMNDP many end-stage kidney disease sufferers in India died without receiving appropriate renal replacement therapy [8], the direct and indirect costs of treatment, including loss of income, continue to cause significant financial hardship for affected families. For this reason, it is recommended that end-stage kidney disease patients be provided more counselling on both the medical and financial implications of treatment [6].

From an ethical perspective, resource limitations provide a challenge for healthcare providers. Ethical guidance documents state that lack of resources should not influence referral to dialysis services for patients with end-stage kidney disease [7]. However, studies have found that concerns regarding patient finances and insurance contribute to physicians’ non-disclosure of chronic disease

Authors: **Evie Kendal** (corresponding author — ekendal@swin.edu.au), Swinburne University of Technology, SPW Level 2, John St Hawthorn VIC, 3122, AUSTRALIA; **Rohin Bhatt** (rohinbhatt1998@gmail.com), Master of Bioethics candidate, Harvard Medical School, Boston MA, USA.

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diagnoses, including cancer and chronic kidney disease [9]. For example, when faced with two patients with similar conditions, the one perceived to have more financial resources may be referred to dialysis services while the other is recommended conservative care only. This diminishes decision-making opportunities for patients, who are best placed to make choices in line with their values and personal situation. Financial influences on dialysis referral and uptake are seen not only among patients from low- and middle-income countries, but also socio-economically disadvantaged sub-populations within high-income countries with universal health coverage [10]. This article will consider the high costs of dialysis for patients experiencing extreme poverty, in light of the ethical principles of informed consent and truth-telling. While these are certainly not the only ethical considerations of importance here, they represent central concerns in modern medical practice and bioethics.

### **Informed consent: General requirements**

In 2017, Brennan et al published the paper "Time to improve informed consent for dialysis: An international perspective" [11]. This article claimed there was widespread failure among nephrologists and other healthcare workers to promote autonomous decision-making among patients with chronic and terminal kidney disease, suggesting patients were typically being "told when they will need dialysis," rather than being informed of all their treatment options and given an accurate description of the likely risks and benefits of dialysis [11]. These authors found that patient expectations were not being met with regard to the level of information provided to aid treatment decisions, noting nephrologists had an ethico-legal obligation to explain "[1] the nature of dialysis, [2] relative risks associated with dialysis and [3] alternatives to dialysis," including conservative, non-dialytic management [11]. In response, a flowchart was developed to help healthcare providers gain informed consent from renal patients. Brennan et al's paper provides valuable groundwork for the current discussion of promoting patient autonomy in resource-limited settings; however, while it is international in scope, it predominantly focused on high-income countries where dialysis is widely available. The following discussion will explore whether extreme poverty poses an insurmountable barrier to autonomy and informed consent for patients with end-stage kidney disease, using Brennan et al's framework as a reference point for achieving legally valid informed consent. The novelty of our approach here is that we argue full and detailed disclosure of all relevant treatment options is not necessarily required for informed consent to be obtained, with a graduated method of disclosure that includes the financial implications of treatment potentially representing a more patient-centred approach.

### **Extreme poverty and impacts on decision-making capacity**

The first relevant consideration here, is whether extreme poverty in and of itself impacts decision-making capacity. We argue that it does not. While uraemic symptoms of confusion

or classical signs of dementia may impact patient competence, poverty, even in the extreme, does not diminish a patient's ability to retain and process information, or their capacity for cognitive reasoning. This does not negate the fact that extreme poverty may cause greater levels of vulnerability among these patient populations, as will be discussed shortly, but in the absence of other impediments, the presumption of competence among adult patients should be retained. As opposition is not anticipated on this point, for the remainder of this discussion we will assume patients in resource-limited settings are to be considered competent in an equivalent manner to those from high-income settings.

### **Poverty as coercion**

The second consideration is how voluntary choices can be made under potentially coercive conditions of poverty. This is where increased vulnerability might seem to obviate genuine freedom of choice. For an action to be considered voluntary typically requires that the agent involved be free from coercion or force and able to freely choose from among a series of options. Force is easily avoidable by, for example, refraining from pushing treatment on a non-consenting patient, or unduly restricting access to available treatments. Under Indian law, the definition of consent must be read from The Indian Contract Act and the decisions of the Supreme Court. The broad principle for free consent that the law lays down is that free consent is given only when there is no threat of fraud, coercion, or undue influence [12]. Ethics demands that the doctor must disclose to the patient, all relevant information regarding the treatments, prognosis, benefits, and costs. Once this information is laid out before the patient, they may autonomously wish to make a choice that is not practically feasible, and if this is due to financial constraints, there is a compelling case to be made that any decision to forego the desired treatment is therefore "coerced". Further, if a choice is considered free only if the agent making it could legitimately have chosen otherwise in the situation, this calls into question whether any financial decision made from a position of extreme poverty can be considered voluntary. The infantilising implications of such a proposition notwithstanding, it must be noted that no patient, irrespective of socio-economic status, makes treatment decisions in a vacuum. Renal patients must weigh up numerous risks and benefits when deciding on treatment options, with one study in Australia demonstrating that patients will sometimes trade increased life expectancy through dialysis for other goals, such as avoiding the need to travel from remote locations to advanced treatment facilities [11]. It is likely some of these patients would have chosen differently had services been available in their local hospitals, thereby indicating their choice to refuse dialysis was potentially "coerced" by the circumstances of having limited care available in remote areas. As such, while the case for financial coercion is strong in resource-limited settings, this is not a *unique* challenge to

informed consent. As Ladin et al describe it, “[d]ialysis is an optional, preference-sensitive treatment” [13]. Even if this one option is not feasible for a given patient, either due to cost or location, this does not undermine the capacity for voluntary decision-making in general.

### **Poverty and obligations of truth-telling**

The final consideration is whether extreme poverty negates the obligation to provide sufficient information to patients regarding dialysis in contexts where they cannot reasonably afford it. This is sometimes justified by physicians in resource-limited settings as being the more compassionate choice, since hearing about a treatment that is financially out of reach might cause psychological distress. There are a number of obvious concerns here, including that physicians might be making assumptions about a patient’s financial status that are untrue, eg they might have a wealthy relative they could approach to pay for dialysis, or they might choose to go into debt to fund their treatment. The norm of truth-telling in the doctor-patient relationship is also violated in this scenario, which could be particularly problematic if the patient or their family then learns of dialysis from other sources. As we have previously demonstrated, if a patient is supposed to make a free and informed decision about the course of treatments, doctors need to lay out all relevant options before their patients and not withhold information. When discussing appropriate ways to inform patients of treatment options, including dialysis and conservative care, Piccoli et al claim a paternalistic approach tries to influence a patient to select the option the physician believes to be best, which might incorporate judgments about financial ramifications of treatment decisions, while a holistic approach involves “presenting information honestly but not necessarily impartially” [14]. These authors claim a more impartial, informative method is often perceived to lack empathy, while a dynamic model “offers a choice of all the feasible options... [and] discusses with the patient how to adapt the options to their needs and preferences” [14]. As such, the treatment chosen is a compromise between the best medical option and “a reasonable, but more feasible one” [14]. We argue there is no reason to exclude financial feasibility in this dynamic model. Although extreme poverty might effectively remove the option of *choosing* dialysis for some patients, a failure to disclose the existence of this treatment functionally removes their ability to *refuse* this option too. In terms of moral agency, it is important to remember that the physician is not responsible for causing the first obstacle to free choice (poverty); however, they are directly implicated in limiting patient autonomy in the second (through withholding information). In short, a lack of choice by patient circumstance should not be compounded by a lack of choice by physician design. We argue the level of information about a treatment option a patient receives should be driven by that patient’s needs. This will sometimes include a request not to hear all the details of a treatment option that is not financially feasible, but this should be determined by the patient, not the

assumptions of their healthcare providers. In this way, physicians would not be withholding pertinent information the patient needs to make an informed choice, as for some individuals the only relevant facts influencing their decision are the costs of a proposed treatment.

Having established that minimum thresholds for informed, voluntary consent are possible even in the face of extreme poverty, we can now address how physicians might gain financial consent for treatments in resource-limited settings.

### **Financial consent and financial toxicity**

Patients with chronic kidney disease are known to suffer physically, psychologically and economically in a manner that has been likened to that of cancer sufferers [15]. In 2013, Zafar and Abernethy coined the phrase “financial toxicity” to refer to the quality-of-life impacts of large out-of-pocket medical expenses for cancer treatment [16]. Here we can apply the same analysis to high-cost dialysis treatment. Zafar and Abernethy relate stories where cancer patients have described “spending their savings, canceling vacations, and working more hours in order to afford their cancer care,” claiming “life-altering, cost related complaints” now form part of the cancer experience for patients [16]. Despite this, these authors note oncologists are not trained to deal with the supposedly “toxic” financial side effects of expensive cancer therapies, which include both the “objective financial burden” of treatment and the “subjective financial distress” that collectively lead to poor quality of life and lower quality care [16]. Some argue the same lack of training exists for nephrologists faced with the ethical dilemma of discussing dialysis with patients for whom it would represent a significant, or unmanageable, economic burden [17].

When considering informed consent [15–18] in the context of potential financial toxicity, or catastrophic health expenditure, the issue of financial consent arises, eg should physicians be obligated to disclose the risk of financial harms of treatment options alongside possible physical harms? If we consider “material risk” in the way Brennan et al do in their framework and the requirements under the law, a patient should be warned of any risk they are “likely to attach significance to,” including ones necessitating a change in lifestyle [11]. Zafar and Abernethy note that cancer patients sometimes lament that they can no longer afford to “do anything,” [16] while dialysis patients often describe their treatment regime as a kind of “prison” [14]. Both responses indicate substantial impacts on lifestyle and quality of life measures. In terms of dynamic information exchange, Zafar and Abernethy advocate for transparency when discussing treatment costs with patients and negotiating reasonable trade-offs when a patient is unable to afford a more expensive option [18]. Suggesting cost considerations be integrated into practice guidelines, these authors believe it is possible to make “cost conscious decisions that are still within the scope of acceptable,

standard care" [18]. While they draw their sample from American cancer patients with health insurance, the same principles can be applied to renal patients experiencing extreme poverty, especially in regions for which only conservative or palliative care for end-stage kidney disease is considered standard care. It is also important to note that neither the right to choose or refuse a treatment carries with it a positive right to demand access to that treatment, including in a resource-limited setting [19]. Furthermore, if allowing financial toxicity to be considered a potential risk and harm of treatment, physicians might be justified in refusing access to dialysis on the grounds that the expected benefits do not outweigh the potential (economic) risks. This brings about a situation in which physicians might be ethically obligated to discuss the option of dialysis, while being simultaneously ethically obligated to refrain from referral on the grounds that it would cause significant financial harm to the patient, or their loved ones. Dilemmas surrounding a conflict between providing best medical care and avoiding financial harm have already been reported in the case of undocumented migrants in the United States, of which Wack and Schonfeld claim 91% can access emergency dialysis under Medicaid, but only 51% routine treatment [20]. While outpatient care is medically preferable to waiting until emergency conditions are met, the financial ramifications for the uninsured are such that suboptimal care might yield better overall cost/benefit analysis. This demonstrates that risks and benefits have to be considered on an individual level, paying close attention to patient values and preferences.

Whether nephrologists and other healthcare workers have an ethical obligation to advocate for more affordable care for renal patients falls outside the scope of this discussion but suffice it to say the removal of financial barriers to treatment in resource-limited settings is not the only method of improving outcomes for these patients. Doctors must have frank discussions with the patient about their financial situation and the possible courses of treatment as a means to further patient autonomy. Promoting autonomy and the feeling of control over treatment decisions is expected to improve wellbeing even in cases where patients are unable to access expensive options, including life-sustaining dialysis.

### **The challenge: Promoting autonomy and truth-telling in the face of extreme poverty**

Promoting autonomy among end-stage kidney disease patients involves respecting patients' unique situations, values and preferences. According to Brennan et al, in high-income settings, like Canada and Australia, there is a recognised legal obligation for physicians to provide patients with information about their three main options: dialysis, conservative care, and renal transplantation [11]. The authors quote Justice Kirby, who claims in the absence of such relevant information "[a]ny choice by the patient...is meaningless" [11]. It is well established that a competent patient can refuse medical interventions, and that physicians

are under no obligation to provide futile or harmful treatments, but there can be significant disagreement regarding the relevant risks and benefits of a proposed treatment, especially if the cost of some treatment options is prohibitive. However, any argument that patients in a resource-limited setting should be denied access to *information* about dialysis on the grounds that it might not be financially viable for them, suggests that patients for whom a compatible match has not yet been found should be denied knowledge of renal transplantation. This attitude is particularly problematic in the light of evidence that most patients want to know details of their illness and options, even if the news is bad [11]. There is also a legal duty on the doctors to lay out all the options before them including the prognosis, treatment options, alternatives and the potential risks and benefits [21].

Handling disclosure of the financial details of treatment options in a way that empowers patients, even in the face of extreme poverty, represents an ethical challenge. Cassidy et al suggest ascertaining patients' "preferences for the quantity and type of information desired with every visit," noting the need to assess "patient readiness to receive information" while also allowing sufficient time to reflect on options and make decisions [22]. We argue in favour of making graduated disclosure the norm, with patients in resource-limited settings being able to decide for themselves what information they wish to receive. This method, already practised in some regions when discussing non-subsidised cancer therapies, could be adapted for renal patients using the general outline below:

- First, a discussion of disease diagnosis and prognosis, including a description of how the disease naturally progresses without intervention and what can be offered to make the patient more comfortable.
- Next, the patient will be asked whether they wish to hear about conservative or palliative care options, after being told roughly what these options cost.
- If the patient consents to learning about these options they will be discussed and then the patient will be asked whether they wish to hear about dialysis or other potential treatments, again following some indication of what the cost might be.
- The treatments should be presented in order of increasing cost. Discussion will continue until the patient either requests no further disclosure or the relevant options have been exhausted.

This method respects a patient's right to know all the available options, but also respects their right *not* to know or hear detailed descriptions of options they cannot afford, should they prefer this. Researchers note it is important to make clear to patients that conservative care does not mean "medical abandonment," [11] but rather preservation of "residual kidney function" [14]. As such, it is not offered in

contrast to dialysis and other expensive options, but rather always in concert. It makes sense, therefore, to outline these care options before broaching the topic of dialysis. To meet the requirements for truth-telling, an accessible summary of dialysis can be provided using the above method, alongside its rough cost estimate, with the patient determining what they wish to hear further about this treatment option, if anything. This is in line with Cassidy et al's suggestion regarding the "quantity and type" of information desired, keeping in mind that a patient can change their mind in future encounters and request information they had previously asked not to have disclosed in detail [22]. Instead of making the patient hear all the details of an intervention they know they will not be able to afford, or worse, learning the financial constraint only after hearing all of this information, this method balances the needs for disclosure in a personalised way. In terms of securing informed consent, we argue the level of detail required to gain informed consent for a treatment option going ahead, in terms of its specific processes and potential side effects, is much higher than the level of information a patient may need to identify an option is financially toxic to them. Importantly, when the patient is in control of the exchange, the health practitioner is not withholding information based on their own assumptions about what is in the best interest of the patient.

The following hypothetical discussions between Dr Diya and her patient, Prashant, who lacks the means to fund dialysis treatment, highlight the contribution adopting this method of graduated disclosure as standard practice might make:

### **Scenario 1: no graduated disclosure**

*Dr Diya: Given your diagnosis, I recommend dialysis. This involves the use of a machine that can clean your blood, as your kidneys are no longer able to do this effectively. You would need to come into the clinic for three-hour sessions, three times a week. Common side effects of the treatment involve bloating, muscle cramps and difficulty sleeping. However, the treatment could extend your life by 5-10 years.*

*Patient Prashant: I don't think I can afford to take that much time off work. Also, is there a cost for this treatment?*

*Dr Diya: Unfortunately, the out-of-pocket expense is X.*

*Prashant: I can't afford that.*

*Dr Diya: Ok, so we can talk about conservative care options instead then...*

### **Scenario 2: graduated disclosure**

*Dr Diya: Given your diagnosis, without treatment we expect to see your kidney function continue to deteriorate and your symptoms to become more severe. We will provide advice on things to make you more comfortable and manage your symptoms that can be done at home with minimal expense. We can also discuss conservative care options available through our clinic. These would cost approximately X per week. Would you like to hear more about these options?*

*Patient Prashant: Sure*

*Dr Diya: We can arrange a dietician to help with your nausea and appetite issues, treat your anaemia, closely monitor your fluid balance, etc. It is difficult to estimate how much time this will give you, but it could be days to weeks. We also have a machine available at the clinic, called a dialysis machine, that can fulfil some of the role your kidneys used to. This would cost Y per week. Would you like to hear more about this option or have any specific questions?*

*Patient Prashant: I can't afford that. I'll just stick to what you said before.*

Although in both cases Prashant ultimately receives conservative care, in the second example they learn of this option in a way that does not automatically cast it in an inferior light. They also had the opportunity to ask for specific information that might be relevant to them, such as life expectancy on dialysis, but did not have this information forced upon them when the benefits are not personally achievable, given their financial situation. Dr Diya has not arbitrarily chosen to withhold information from Prashant here, so they will not stumble across dialysis in their own research and feel betrayed. For this patient, the financial consideration has already disqualified this treatment option for their personal circumstances, so it is not meaningful to provide them details of dialysis session times or side effects. This patient is still able to choose to hear such details about dialysis, even knowing they won't be able to afford it, if they prefer to have the information anyway. But unlike in the first scenario, they are not put in a situation where the knowledge has been provided without the essential financial context, and left to bring up the cost themselves, only to discover the treatment will not be feasible for them.

Importantly, this form of graduated disclosure incorporating financial information need not be limited to end-stage kidney disease or cancer patients, but rather could be applied in any treatment context in which out-of-pocket expenses are anticipated. This would apply in both high and limited resource settings, and to existing and novel interventions, with a particular focus on chronic conditions as these are the ones likely to involve ongoing health expenditure. While this is undoubtedly already occurring in practice, the lack of a systematised approach to conducting and analysing this method needs to be redressed. While it is beyond the scope of this paper to suggest means of evaluating the potential efficacy of the approach, we advocate for future studies that look at this issue. We will now move on to address the most likely objection to this proposal, in terms of obstacles to patient autonomy.

### **Objection: Presenting artificial choices**

One anticipated objection to the arguments presented here regarding promoting patient autonomy through graduated disclosure of end-stage kidney treatment options, including dialysis, to patients in resource-limited settings, revolves

around whether we are just presenting artificial choices. To answer this objection, it is first necessary to establish that not all patients with access to dialysis choose to use it, and the patterns of refusal have changed over time in line with renewed focus on patient-centred care and autonomy [23]. It is also the case that while it is life-sustaining, dialysis is not necessarily considered a quality of life enhancing treatment [24], with many dialysis patients reporting symptoms of depression and anxiety [25]. Some patients refuse dialysis on mental health grounds, or for social reasons that are quite distinct from financial considerations [19], and it would be impolitic to assume all patients in extreme poverty might refuse dialysis purely on financial grounds. Seah et al's investigation of the reasons behind dialysis refusal among end-stage kidney disease patients in Singapore, indicated "cultural values of collectivism and interdependence in Asian cultures" were influencing decision-making, in addition to knowledge of others' "lived experiences" of dialysis causing poor quality of life [26]. Similar cultural values and definitions of selfhood in relation to kinship ties would need to be considered when presenting treatment options to patients in India and other countries where dialysis demand is currently significantly outstripping supply. Also, while Seah et al noted "[f]inancial concerns were vividly voiced" among participants in their study, physical and time costs were also factors in refusing dialysis [26]. Even if financial considerations were the major reason patients experiencing poverty refused dialysis, the evidence still suggests patients prefer to know about their options and feel more in control of their treatment journey [27]. For some, feeling in control might also include limiting information exchange regarding treatment options they deem inappropriate for their situation, including their socio-economic situation. It is also important to note here that while excluding patients from dialysis programmes is usually done for medical considerations, socio-economic status, and particularly extreme poverty, has been used as grounds to exclude some patients in resource-constrained settings [28].

Piccoli et al claim that patients involved in shared decision-making over their care "appeared more confident and satisfied with decisions" than those who felt "pushed into a choice," [14] which would presumably include those who felt assumptions about their financial status were influencing how treatment options were framed or whether they were disclosed at all. Even in cases where patients have a terminal diagnosis, studies show truth-telling from their physician is expected and welcome, and that patients value being able to plan their remaining time and, where relevant, engage with cultural and religious rituals for the end of life [27]. It seems implausible that financial disclosures can sometimes be more sensitive than a terminal diagnosis.

## Conclusion

Resource limitations pose practical and ethical challenges for healthcare workers serving the needs of end-stage kidney disease sufferers around the world. Such constraints have

often been shown to result in moral distress for nephrologists [29]. Patients experiencing extreme poverty have the right to be made aware of relevant treatment options as well as their financial implications, with graduated disclosure providing one method of promoting patient autonomy while minimising potential distress associated with providing detailed knowledge of unobtainable options. This type of medical and financial disclosure should be the norm when dealing with treatments for which there is an expected out-of-pocket expense, including dialysis.

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