Review Article

Decision-making around Commencing Dialysis

Indu Ramachandra Rao, Nandini Vallath[1,2,3], YJ Anupama[4], Krishan Lal Gupta[5], Krithika S. Rao[6]

Departments of Nephrology, [6]Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal, Manipal Academy of Higher Education, Manipal, [4]Department of Nephrology, Nanjappa Hospital, Shivamogga, Karnataka, [5]Department of Nephrology and Renal Transplantation, Postgraduate Institute of Medical Education and Research, Chandigarh, [2]Palliative Care, BARC Hospital, Mumbai, Maharashtra, India, [3]Palliative Care and Division of Medical Humanities, KEM Hospital, Mumbai, Maharashtra, India, [1]Division of Palliative Care, National Cancer Grid, India

Abstract

The decision regarding dialysis initiation is complex. Awareness that renal replacement therapy should not be regarded as default therapy for every patient with advanced renal failure is necessary. Decision to initiate dialysis and modality should be individualized in a shared decision-making process involving the treating nephrologist and the patient. Patients should receive predialysis education early in the course of chronic kidney disease so as to help prepare them well in advance for this eventuality. Withholding dialysis may be a reasonable option in a certain subset of patients, especially elderly patient with multiple co-morbid illnesses. Comprehensive conservation care should be offered in all patients where the decision to not dialyze is taken.

Keywords: Dialysis, end-stage kidney disease, palliative care, renal supportive care, shared decision-making

Introduction

Chronic kidney disease (CKD) is associated with progressive deterioration in kidney function. Management in early stages involves measures to prevent rapid progression of disease and optimize medical management with aim to minimize complications and preserve functions of the various organ systems in the patient. Some form of renal replacement therapy (RRT), either dialysis or renal transplantation maybe be required in the fifth stage of the disease. Approach to RRT is decided based not only on the health condition of the patient, their social and financial resources but also by the health care setting, in which they receive care. In suitable patients, successful renal transplantation offers a good quality of life, with improved physical and mental health and functionality including sexual function. Hemodialysis and peritoneal dialysis are modalities available for those with poor prospects for a renal transplant. There is also a subset of patients for whom conservative care alone may be appropriate. Given the enormous socioeconomic and medical implications of RRT, discussions regarding the options are ideally begun early in course of disease.

In Indian nephrology practice, when a patient has end-stage kidney disease (ESKD) several scenarios may unfold. The first is that RRT is recommended and commenced. The second is that it is recommended but that RRTT is either not available or affordable. In this second scenario the patient, not through medical recommendation, but circumstance, commences a conservative, nondialysis pathway. The extent to which this situation is changed through the Pradhan Mantri National Dialysis Program remains to be seen. This article aims to provide recommendations to support appropriate decision-making on commencing dialysis and reviews the scientific evidence for identifying subset of patients in whom RRT option may need reconsideration. It is hoped that the contents encourage professional teams to begin engaging with patients/families and facilitate shared decision-making as a critical process toward better care planning of end-stage renal disease (ESRD) patients.

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Address for correspondence: Dr. Nandini Vallath, Palliative Care Consultant, National Cancer Grid- India, Tata Memorial Hospital, Parel East, Parel, Mumbai, Maharashtra – 400 012, India.
E-mail: aanandini@gmail.com

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Is there a Subset of Patients for Whom Long-term Dialysis May Not be the Best Option?

It may be inaccurate to assume that dialysis, by substituting for renal functions would uniformly improve the survival and quality of all ESRD patients. Evidence suggests that there are certain clinical situations where dialysis as an option may need to be re-evaluated.

Survivorship advantage

Although it is well known that the mortality of dialyzed patients is worse than that of the general population, it was assumed that survival of ESRD patients on regular dialysis was significantly higher than those who were not. Over the last decade, this assumption has been questioned by several researchers who found that in the elderly (age >75 years) with multiple comorbidities-in particular, those with ischemic heart disease, there was no significant survival benefit of dialysis.[1-3]

Symptom burden and quality of life of patients on dialysis

Dialysis although expected to control the symptoms caused by poorly functioning kidney, may add to the symptom burden.[4-6] Dialysis is also associated with decreased quality of life and increased risk of hospitalizations among elderly patients on dialysis versus conservative care.[7,8] Carson *et al*. noted that approximately 80% of the extra days survived, were spent either on dialysis or being hospitalized for complications of dialysis. The average days of hospitalization, outside of the dialysis related visits, were roughly a month/year, whereas those on conservative care were admitted for half of those days/year.[8]

Burden on caregivers

Dialysis potentially affects routines of patients and family both in professional and personal terms. There are emotional, financial and social consequences of long-term care with logistics of travel, cost, time off work and financial burden, all of which can be devastating to an average Indian family. Belasco *et al*. observed high caregiver burden, with worsening of the caregiver's quality of life with increasing patient age, presence of comorbidities and poorer functional status of the patient.[9]

The following recommendations for decision-making around commencing dialysis are the outcome of the Renal Supportive Care (RSC) workshop held at Kasturba Medical College, Manipal in February 2019. These recommendations represent the opinion of the working committee, backed by evidence where it exists.

Recommendations for decision-making around commencing dialysis

1. Dialysis-related discussions SHOULD be held within the framework of bioethics

   Respect for the individual: confidentiality, privacy, and respect for their beliefs and feelings are basic tenets of ethical care. The values that the patient upholds and what dignity means to them, influence their choices and quality of life. Determining what their expectations are, and what is most important to them in terms of staying alive are important conversations that the nephrology team must have, early in the course of the disease. Useful approaches of enquiry are:

   a. What are your expectations from this treatment?
   b. The dignity question concept-What do I need to know about you as a person, to take best care of you that I can?[10]

The responses of patients provide insight into their values and help determine whether dialysis would indeed meet their expectations; and if life would be in alignment with their expressed values and priorities. Early conversations pave way to deeper interactions and develop pathways for advance care planning.

Supporting informed autonomy

Consent requires that patient be fully informed about all options for treatment and conservative care, and given opportunity to discuss and weigh the consequences of each. The team must ensure full understanding, respect the patient's decision to choose or refuse dialysis and support what's in their best interest. If the patient is incapable of taking a decision, the surrogate/legal agent of the patient, can be empowered to make the decision for him/her.

In India, collective autonomy including the extended family, rather than individual autonomy, prevails. Hence, dialysis-related decisions may involve consultation with the patient's family, if the patient so wishes.

Nonmaleficence

The nephrology team has an obligation to ensure that no harm that is foreseeable is done, by weighing the balance between beneficence from regular dialysis and the burden of therapy, especially from patient's perspective. There is a subset of patients where dialysis cannot be safely carried out, for example, those with multi-organ failure and hemodynamic instability.

Beneficence

Recommending dialysis for any individual patient would be ethical, when reasonable improvement is expected in terms of survival, and quality of life.

Justice

This ethical principle of distributive justice suggests fair allocation of available resources. It guides channelization of limited resources to those with maximum productive years of life. Resources include: (i) the resources of dialysis facility as well as (ii) resources of the family/community. Some patients with ESKD may not receive dialysis for financial reasons. This cohort is choice restricted. This is a significant issue in India.

Real-life clinical situations are complex and often ethical principles may counter each other. In these situations, the treating team would need to engage deeper with the patient and his/her family through the process of "shared decision-making."

2. All CKD-stage 4–5 patients should be empowered to engage fully in decision-making

CKD patients are inadequately prepared for either living with CKD, dialysis or dealing with end-of-life issues.[11,12] It is imperative that patients with CKD/ESRD with its complex disease trajectories, high morbidity, and immense socioeconomic implications, are empowered with information to make empowered decisions on care plans.

The importance of timely and appropriate predialysis education cannot be overstated. It improves patient understanding of the process and directly reduces incidence of unplanned emergency dialysis.[13] Additional benefits of predialysis education include (i) it improves survival, in comparison to those who do not receive it, (ii) gives a better sense of well-being, reduces anxiety and ensures better physical functioning, and (iii) is associated with a higher likelihood of staying employed.[14-18]

It is recommended that dialysis units have educational programs on RRT, trained counselors and supportive care.

The decision to undergo long-term dialysis must be an "informed" one. All patients with estimated glomerular filtration rate <30 ml/min (CKD stage 4 and above) should receive timely and personalized information about.

a. Their disease-the extent, progress, and their position on the CKD trajectory
b. Treatment options-pros and cons of RRT (hemodialysis, peritoneal dialysis or kidney transplantation) and where appropriate, of a conservative pathway. The nephrology team must ensure that the patients have realistic understanding about the commitments, morbidities, survival, and quality of life on dialysis
c. Prognosis-what may be expected with or without the RRT intervention
d. Supportive care-this must be integral to all forms of ESRD care-plan including dialysis, posttransplant, or comprehensive conservative care (CCC).

Communication skills are crucial in facilitating shared decision-making conversations. Open questions, active listening, expressing empathy, exploring thoughts behind verbal or nonverbal expressions, verifying comprehension, summarizing and documenting main points, for patient to review and revert, are all trainable essentials skills to be internalized by RSC team personnel.

3. The approach to dialysis decision-making SHOULD be patient-centered

This recommendation highlights the importance of professionals and patient/family working together to ensure best possible care outcomes. It endorses patient-centered care for refining healthcare outcomes and greater patient satisfaction. Although the treating nephrologist would lead the discussion and empathetically guide decision making, every attempt is to be made to align the treatment plan with patient's preferences and expectations.

4. Consider individual circumstances to initiate or forego dialysis.

Based on biological prospects

In clinical situations where patients may benefit very little or not at all with dialysis, compared to conservative care alone, the treating physician, in consultation with the patient and his/her family, may consider foregoing dialysis.

1. When clinical condition precludes the technical process of dialysis because the patient:
   a. Is unable to cooperate (e.g., advanced dementia)
   b. Unstable medically (e.g., hypotension).
2. Prognostication suggests life-expectancy <6 months, due to life-threatening comorbidities with severe physical, cognitive or functional decline, for example, malignancy, end-stage cardiac/liver/respiratory failure
3. Age >75 years with 2 or more of the following:
   a. When the nephrologists caring for the patient responds with "No" to the question-*Would I be surprised if this patient died in the next year?*'[19] This is an easy-to-apply prognostic tool validated in ESRD patients and helps identifying patients in whom nondialysis conservative pathway is advisable
   b. High comorbidity score-Modified Charlson's score (MCS) >8[20]
   c. Significantly impaired functional status with Karnofsky Performance scale of <40[21]
   d. Severe chronic malnutrition (S. albumin <2.5 g/dL).

These suggestions are based on studies discussed earlier and the latest clinical guidelines.[1,2,8,22-25] The ANZSN RSC Guidelines use Couchoud model and surprise question to guide decisions for nondialysis pathway, especially for the elderly population.[25,26] Use of surprise question, MCS and Cohen score is suggested for dialysis patients with comorbidities, being considered for transition to a nondialysis pathway.[25,27] However, these risk scores have not yet been validated in the Indian CKD population and therefore, their clinical utility in our population needs to be explored.

Based on patient autonomy or advance care directives

Aside from the situations listed above, a "nondialysis" conservative pathway may be adopted when

1. It is a voluntary choice on the part of a fully empowered patient/patient's legal agent to forego dialysis
2. There is an official advance directive in which the patient has explicitly recorded refusal of dialysis, although the decision-making capacity of the patient may be currently compromised.

The choice-restricted group

The Kidney Disease: Improving Global Outcomes Controversies Conference report on Supportive Care in CKD defines "*choice-restricted*" group as patients in whom resource constraints prevent or limit access to RRT.[22] In this group of patients, CCC would be preferable to unsafe precipitous care or no care at all.

5. When decision to forego dialysis has been made, the patient should receive CCC

Patients who are advised, or opt to forego dialysis, along with those from "choice restricted" group should receive CCC. It includes two simultaneous inputs; the competencies of renal medicine aimed to preserve renal function and prevent complications, along with competencies of palliative medicine, to maximize function, minimize symptoms, and maintain quality of life as prioritized by the patient.

Abandonment, quick referral, or a noncommunicative transfer to palliative care is inappropriate.

The patient who made a purely autonomous decision to forego dialysis, must be made aware that the decision to forego dialysis may be re-considered later. The nephrologist may review the patient's decision and support decisions on the course of management at follow-up visits.

6. Time-limited trial (TLT) of dialysis may be offered when benefits of dialysis is uncertain

In situations where the patient/family are unable to make a clear decision, it is reasonable to offer a TLT of dialysis. Length of the trial and parameters for review should be individualized and predetermined to avoid future ambiguity.[24] The decision to forego dialysis may be made at the end of that period, if the patient is responding poorly, has complications, or requests for withdrawal of dialysis.

7. Establish RSC facility to support conservative care needs of CKD/ESRD patients.

All patients are ideally managed by multi-disciplinary team consisting of renal nurse, dietician, palliative care specialist, social worker, and led by the nephrologist. The team provides RSC with trained competencies in communications to identify expectations, goals of care, engage with all stakeholders, and facilitate shared decision-making. Important objective of RSC team would be to develop systems in place; to elicit patient preferences, attend to symptoms and be sensitive to quality of life, within the scope of ongoing disease-modifying interventions and beyond. Guidelines and resources are freely available online.[28] The renal version of the Integrated Patient Outcome Scale (IPOSRenal) and EuroQoL-5D (EQ-5D) are free validated tools to record and prioritize patient concerns.[29,30]

Conclusion

To conclude, decision-making around dialysis is complex and involves considerable stress to the patient as well as family. The patient has to cope with numerous changes in several domains at once-medical, social, and financial. RRT cannot be uniformly prescribed to all patients and the choice as well as modality should be individualized in a shared decision-making process involving all stakeholders. We recommend that the process be initiated early in CKD so that patients can make timely and appropriate choices. It is recommended that nephrology centres develop RSC teams to facilitate coordination between nephrology and palliative care teams, to support decision-making by patients and to ensure a good quality of life. Finally, we recommend that patients on a conservative, nondialysis pathway, for whatever reason, are provided integrated care involving nephrology, palliative care, and primary care.

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Conflicts of interest

There are no conflicts of interest.

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