Withdrawal from Dialysis: Why and When?

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Abstract

Patients with end-stage kidney diseases may request for withdrawal of dialyses for many reasons. Healthcare practitioners frequently puzzled by ethical dilemma of respecting patient's wishes and beneficence of continuing dialysis. Shared decision-making and negotiating goal of care help in decision-making in patients' interests. Proactive identification guidelines that may be used for screening help in weighing options of dialysis and conservative care during progressive decline of clinical condition. Proactive identification guidelines may be used for screening. It helps in weighing options of dialysis versus conservative care during progressive decline of clinical condition. An individualized, patient-centred discussion, rather than disease-oriented, approach may be adapted.

Keywords: Decision-making, dialysis, palliative care, withdrawal

"Whenever the illness is too strong for the available remedies, the physician surely mustnot expect that it can be overcome by medicine ... To attempt futile treatment is to display ignorance that is allied to madness" (Hippocratic Corpus)

BACKGROUND

Hemodialysis (HD) withdrawal is defined as HD discontinuation after an active decision to permanently stop dialysis by the patient, family, healthcare power of attorney, or healthcare team. However, there are currently no uniformly accepted definitions of withdrawal of dialysis. [1] The practice of withdrawal from dialysis also differs significantly between the countries. [2]

In chronic kidney disease 5Ds, questions arise requesting justification of dialysis treatment in terms of therapeutic benefit versus the burden, increasing disease morbidity, and deteriorating quality of life.^[3] In clinical practices, decision to withdraw dialysis therapy arises due to realities such as increasing comorbid conditions, acute medical complications, and increasing logistic burden for family.^[4] Patients and families often feel that long-term dialysis treatment is burdensome and express doubts when the quality of life and health of individuals deteriorate.^[3] Process for approaching patients about dialysis withdrawal is not standardized,

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and the conversation can be emotionally difficult for patient, family members, and nephrologists. With shared decision-making which involves basic principles of ethics, e.g. autonomy, beneficence, nonmaleficence, and distributive justice, withdrawal from dialysis is ethically and clinically acceptable.^[5]

Table 1: Common reasons for HD withdrawal

Multiple HD access failure

Acute medical complications such as frequent hypotension, severe pain or cramps, life-threatening arrhythmias

Chronic debilitating problems

Chronic failure to thrive/frailty

Logistic and financial reasons (long distance travel, belonged to very poor rural/tribal communities, inadequate family support)

HD: Hemodialysis

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In a study by Shaikh *et al.*, 2018, 64% of patients stopped HD and 17% of patients died while on dialysis. Common reason for dialysis withdrawal is listed in Table 1.^[6,7] Dialysis withdrawal has been reported as a leading cause of death in patients on dialysis for chronic renal failure. Death in patients with renal diseases on dialysis has been classified as: [1]

- 1. Death preceded by dialysis withdrawal (cause of death: renal related/uremia)
 - a. Patient choice but not recommended by the treating medical team
 - b. Without significant medical problems other than renal failure
 - Active decision to withdraw from dialysis treatment
 - d. Comorbidity there may not be significant co-morbidity.
- 2. Death preceded by dialysis withdrawal (other causes of death, i.e. malignant disease, Myocardial Infarction)
 - Usually, a shared decision of the medical team and patient/family with significant medical problems other than renal failure
 - b. Comorbidity score usually very high, or in a frail elderly patient.
- 3. Death on dialysis No dialysis withdrawal
 - a. No decision to withdraw from dialysis
 - b. Time from last dialysis until death usually <3 days.

BARRIERS TO INTRODUCTION OF DIALYSIS WITHDRAWAL

For most of patients with end-stage renal disease (ESRD), dialysis is considered standard of care. Family members

Table 2: Psychosocial and communication barriers

Unawareness of option of supportive care

Nonacceptance of other option

Consider withdrawal as death

Consider withdrawal "giving up"

Fear related to society's acceptance

Unrealistic hope about medical condition and prognosis

Lack of decision-making capacity in patient

Fear of outcome on family

Unaccomplished family needs

Financial burden on family

Fear that withdrawal causes destruction of hope

Health care provide factors

Difficulty in estimating patient's prognosis

Lack of communication regarding patient's wishes

Unrealistic expectations about prognosis

Inability to communicate the option of supportive care

Unavailability of trained palliative care/renal supportive care team

Ethical/legal difficulties to withdrawal

Acute presentations to ED

ED: Emergency department

often feel option of withdrawal as giving up, and it will lead to painful death. Many a time, patients and family members have unrealistic hope of cure from the illness.^[7] Physician often finds it difficult to discuss the option of withdrawing from dialysis.^[8] In some conditions, ethical dilemmas and legal process make withdrawal decision difficult for the patient [Table 2].

SCREENING TOOL TO IDENTIFY PATIENTS IN WHOM WITHDRAWAL FROM DIALYSIS CAN BE CONSIDERED

The gold standard framework proactive identification guidance can be used as a screening tool and to guide the healthcare practitioners for whom withdrawal can be discussed [Table 3].^[9] However, withdrawal should be considered only when clinician and team feel that burden of dialysis (nonmaleficence) clearly outweighs the benefit (beneficence). It involves step-wise approach for identification using surprise question, general indicator, and specific indicator for renal diseases.^[10]

Table 3: Gold standards framework proactive identification guidance (Principles and materials for the gold standards framework (c) K Thomas, the National GSF Centre 2003-2019. Used with permission from the National GSF Centre in End of Life Care. http://www.goldstandardsframework.org.uk/)

Step 1: The surprise question

"Will you be surprised if the patient dies in the next year, months, weeks, days?"

Step 2: General indicators of increasing dependence or deteriorating health Generalized deterioration in physical condition, increasing dependence, and needed support for activities of daily living

Multiple unplanned hospital admissions

Advanced CKD with progressive, complicated symptoms

Presence of significant multiple comorbidities

Declining performance status (e.g., Barthel score), unable to do self-care, in bed or chair 50% of day, and increasing dependence in most activities of daily living (Karnofsky performance score ≤50)

Poor response to treatments, decreasing reversibility of disease

Patient's preference for no further active treatment and focus on quality of life (patients autonomy)

Progressive fall in weight (>10%) over the past 6 months

Unanticipated serious event, e.g., frequent/serious fall, death of loved one Serum albumin <2.5 g/dl

Step 3: Chronic kidney disease stage 4 or 5 with deterioration with at least two of the indicators below

Patient for whom the surprise question is applicable

Repeated unplanned admissions (>3/year)

Patients with poor tolerance of dialysis with change of modality

Patients choosing the 'no dialysis' option (conservative), dialysis

withdrawal or not opting for dialysis if transplant has failed

Difficult physical or psychological symptoms that have not responded to specific treatments

Symptomatic renal failure in patients who have chosen not to dialyze nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload

CKD: Chronic kidney disease

Table 4: Step-wise approach for implementation of withdrawal from dialysis

Identify decision-maker for the patient (patient or family member)
Assess patient's decision-maker's understanding of the patient's clinical situation and benefit versus burden of disease

Provide explanation to the patient/family caregiver for dialysis withdrawal and rationale for it

Reassess the understanding and decision, ensuring consistency in family caregiver

Introducing palliative care services and explaining their scope in the management of the patient

Documentation of decision of withdrawal on medical records and inform primary care physician, nephrologist, and palliative care team

Implementation of withdrawal from dialysis and shifting focus of care to comfort and symptom control of patient and provision of dignified end of life care

Exploring conflict and taking steps toward conflict resolution and review the care process

Provision of bereavement care for the family members

RECOMMENDATIONS FOR WITHDRAWAL OF DIALYSIS (KIDNEY DISEASE: IMPROVING GLOBAL OUTCOMES GUIDELINES)

In 2015, Kidney Disease: Improving Global Outcomes (KDIGO) developed a roadmap for improving care for patient of ESRD. KDIGO guidelines^[11] highlighted the process of introducing conservative care for patients who opts for withdrawal from dialysis. We proposed step-wise approach for withdrawal from dialysis and implementation of end-of-life care pathway^[12] [Table 4].

COMMUNICATION AND IMPLEMENTATION OF WITHDRAWAL OF DIALYSIS

The communication regarding withdrawal of dialysis treatment can be challenging and stressful for all, patients, family members, and physicians. This discussion should be conducted in appropriate setting and involving all decision-makers for patients. Patient's primary care physicians and palliative care team can also be involved in discussions. During the conversations, patient's and family members' understanding of disease should be assessed and the physician should help the patient or family members in shared decision-making process. The details of discussion must be documented clearly on patient's medical records and should be informed to the people involved in his care.

CONCLUSION

As the clinical condition of ESRD patients on dialysis deteriorates, with the worsening of performance scores and

comorbidity, patient-specific evaluation of burden versus benefit of continuation of HD should be considered by nephrologists. Shared decision-making process with patients and family members will provide opportunity to discuss patient's wishes, goals of care, and option of withdrawal from dialysis to ensure comfort and a dignified, end-of-life care. Palliative care teams should be involved to provide holistic care for the patient.

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