### **REVIEW ARTICLE**



# Changing landscape of dialysis withdrawal in patients with kidney failure: Implications for clinical practice

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### **Abstract**

Dialysis withdrawal has become an accepted treatment option for patients with kidney failure and is one of the leading causes of death in patients receiving dialysis in high-income countries. Despite its increasing acceptance, dialysis withdrawal currently lacks a clear, consistent definition. The processes and outcomes of dialysis withdrawal have wide temporal and geographical variability, attributed to dialysis patient selection, influence from cultural, religious and spiritual beliefs, and availability of kidney replacement therapy and conservative kidney management. As a complex, evolving process, dialysis withdrawal poses an enormous challenge for clinicians and healthcare teams with various limitations precluding a peaceful and smooth transition between active dialysis and end-of-life care. In this review, we examine the current definitions of dialysis withdrawal, the temporal and geographical patterns of dialysis withdrawal, international barriers in the decision-making process (including dialysis withdrawal during the COVID-19 pandemic), and gaps in the current dialysis withdrawal recommendations for clinical consideration and future studies.

#### KEYWORDS

decision-making, dialysis withdrawal, kidney failure, medical ethics, palliative care

### SUMMARY AT A GLANCE

This review consolidates some of data around the definitions and challenges of withdrawing dialysis. It explores differences in global interpretation of the concepts and practice, and touches upon how COVID-19 has influenced this subject.

### 1 | INTRODUCTION

Withdrawing from dialysis is becoming increasingly accepted as a treatment option since Neu and Kjelistrand first published the pivotal study on stopping long-term dialysis in 1986.<sup>1</sup> Dialysis withdrawal is one of the leading causes of death in patients with kidney failure in high-income countries (HICs),<sup>2-4</sup> and older patients are

much more likely to withdraw from dialysis compared to younger patients.<sup>5</sup> Despite numerous guidelines providing recommendations for the dialysis withdrawal process, there is considerable variability in the current clinical practices between and within countries.<sup>6–8</sup> Comprehensive conservative kidney management (CKM) has been developed over the past two decades and is now easily accessible in HICs to facilitate the process of dialysis withdrawal.<sup>9,10</sup> However,

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such services are often limited in middle- (MICs) or low-income countries (LICs). <sup>10</sup> Dialysis withdrawal in these countries and ethnically diverse populations remains poorly understood due to competing social, cultural, and economic barriers. <sup>11–14</sup> With the increasing incidence of dialysis in MICs and LICs, the practice of dialysis withdrawal will likely increase over time in these countries. This review focuses on the current understanding of dialysis withdrawal, explores potential barriers for dialysis withdrawal, and identifies gaps in the current dialysis withdrawal recommendations. Conservative pathway for patients who have never initiated on dialysis has been examined extensively in the literature and will not be covered in this review. <sup>9,15–20</sup>

### 2 | DIALYSIS WITHDRAWAL

### 2.1 | Definition of dialysis withdrawal

The lack of a unitary definition of dialysis withdrawal has posed enormous difficulties in the attempt to understand the processes and outcomes of dialysis withdrawal.<sup>21-23</sup> Figure 1 and Table 1 provide a summary of the definitions of dialysis withdrawal classified by the reasons for withdrawal and causes of death. Country-specific registry studies often define dialysis withdrawal by reasons for withdrawal, irrespective of the underlying cause of death by kidney failure or comorbid conditions, 5,23-32 with the exception of the United States Renal Data System.<sup>2,33-36</sup> Dialysis withdrawal is classified as per reporting personnel in registries, and the risk of misclassification and oversimplification is high, especially when only a single cause of death is reported without the details of death. The main outcomes examined are temporal trends and risk factors for dialysis withdrawal which have implications on recourse allocation and healthcare strategies. On the other hand, single- and multi-centre studies often define dialysis withdrawal as death from kidney failure after discontinuation of dialysis, excluding patients who withdraw dialysis for other terminal medical

conditions.<sup>1,37-42</sup> These studies aim to differentiate psychosocial details and to assess the experience of dialysis withdrawal. The inconsistent definitions between national registries and research studies likely included patients with different underlying phenotypes. When making the decisions regarding dialysis withdrawal based on current evidence in the literature, appreciating different definitions of dialysis withdrawal provides a better understanding of potential contributing factors, barriers to dialysis withdrawal, and cultural and ethico-legal implications.

### 2.2 | Evolution of dialysis withdrawal

The temporal changes of dialysis withdrawal have evolved gradually over the last 50 years since maintenance dialysis first became available. In the 1960s and 1970s, the main focus for dialysis therapy was promoting its survival benefits and expanding accessibility. 43 Despite the aspiration to promote the benefits of dialysis, the reality of the restrictive cost burden meant that dialysis was restricted to those with a low comorbid burden. Due to inadequate understanding of patients' experience, dialysis withdrawal was regarded as treatment non-adherence and maladaptation. 43,44 With increased accessibility of dialysis over time, more patients with limited life expectancy were offered kidney replacement therapy (KRT). This shift in patient selection resulted in increased symptom burden, dialysis-associated complications, and mental health concerns. 45,46 In recent years, the emerging emphasis on patient autonomy and shared decision-making process prioritizes patient-oriented quality of life, replacing the conventional focus on preserving survival benefits. Consensus guidelines based on expert opinion and current literature were published by Renal Physicians Association-American Society of Nephrology (RPA-ASN) in 2000 and by Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference in 2013. These guidelines further consolidated the acceptance of dialysis withdrawal, provided a conceptual framework to assist clinicians' approach to dialysis withdrawal, and highlighted the need for future research work to

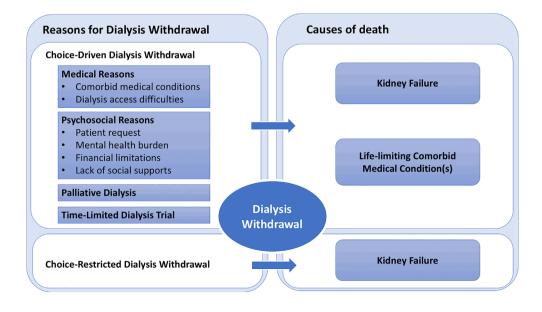


FIGURE 1 Types of dialysis withdrawal, classified by reasons for dialysis withdrawal and causes of death

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	Reasons for di	Reasons for dialysis withdrawal	'al				Cause of death	leath	
	Medical reasons	SI	Psychosocial reasons	reasons					
Literature	Comorbid conditions	Dialysis access	Patient request	Mental health	Financial limitations	Lack of social supports	Kidney failure	Comorbid condition	Definition
Registry studies									
Dialysis Outcomes and Practice Patterns Study (DOPPS) Fissell et al., $2005^{24}$ Jassal et al., $2020^5$	Not specified						Not specified	pə	Dialysis withdrawal defined as per data entry personnel
United States Renal Data System (USRDS) Wetmore et al., 2018 <sup>33</sup> Wetmore et al., 2019 <sup>34</sup> Wetmore et al., 2020 <sup>35</sup> Roberts et al., 2021 <sup>36</sup>	<b>√</b> es <b>∕</b>	γes γ	<b>∖</b> es <b>∕</b>	Not specified 'Dialysis with	Not specified Dialysis withdrawal for other reasons'	er reasons'	<b>≻</b> es <b>≻</b>	<b>\</b> es <b>\</b>	1986–1990: Dialysis withdrawal defined as per data entry personnel 1990–2004: Dialysis withdrawal as a cause of death was removed. Dialysis discontinuation prior to death was reported with reasons for discontinuation 2004-Current: Dialysis withdrawal defined as 'withdrawal from dialysis/ uraemia' with reasons for discontinuation ('access failure', "failure to thrive', 'acute medical complication', or 'other'), patient request, and date of last dialysis
Australian and New Zealand Dialysis and Transplant (ANZDATA) registry ^Chan et al., 2012 <sup>25</sup> Chan et al., 2021 <sup>27</sup> Khou et al., 2021 <sup>27</sup> Chen et al., 2021 <sup>28</sup>	<b>√</b> es <b>∕</b>	γes γ	<b>√</b> es <b>∕</b>	Not specified 'Dialysis with reasons'	Not specified 'Dialysis withdrawal for psychosocial reasons'	chosocial	Not specified	pa	Pre-October 2003: Dialysis withdrawal defined as 'patient refused further treatment' or 'other reasons' Post-October 2003: Dialysis withdrawal defined as 'psychosocial reasons', 'patient refused treatment', 'cardiovascular comorbid conditions', 'cerebrovascular comorbid conditions', 'peripheral vascular comorbid conditions', 'malignancy', or 'dialysis access difficulties'
Canadian Organ Replacement Registry (CORR) Ellwood et al., 2013 <sup>29</sup>	Yes 🗸	<b>x</b> o Z	Yes 🗸	Not specified 'Dialysis with	Not specified Dialysis withdrawal for other reasons`	er reasons'	Not specified	pe,	
UK Renal Registry Ansell et al., 2010 <sup>30</sup> Pyart et al., 2020 <sup>31</sup>	≺es ≺		Υes <b>≺</b>	Not specified 'Dialysis with	Not specified 'Dialysis withdrawal for any other reason'	other reason'	Not specified	eq	Using ERA-EDTA coding: 'patient's refusal of further treatment', 'dialysis withdrawal for medical reasons' or 'dialysis withdrawal for any other reason'

TABLE 1 (Continued)

	Reasons for d	Reasons for dialysis withdrawa	ıwal				Cause of death	eath	
	Medical reasons	ııs	Psychosocial reasons	al reasons					
Literature	Comorbid conditions	Dialysis	Patient request	Mental health	Financial limitations	Lack of social supports	Kidney failure	Comorbid	Definition
Scottish Renal Registry Findlay et al., 2016 <sup>23</sup>	Yes 🗸		≺es <b>≺</b>	Not specified Dialysis withd	Not specified Dialysis withdrawal for any other reason/n	other reason/n	Not specified	pe	Using ERA-EDTA coding: 'patient's refusal of further treatment', 'dialysis withdrawal for medical reasons' or 'dialysis withdrawal for any other reason'
Dutch registry of kidney replacement therapy (RENINE) van Oevelen et al., 2021 <sup>32</sup>	Yes 🗸		Yes 🗸	Not specified Dialysis withd	Not specified Dialysis withdrawal for any other reason	other reason	Not specified	Þ	Using ERA-EDTA coding: 'patient's refusal of further treatment', or 'dialysis withdrawal for medical reasons or any other reason'

Multi-centre studies							
Roberts & Kjellstrand, 1988 (USA) <sup>139</sup>	× ° Z	×°S	Not specified 'Dialysis with	Not specified 'Dialysis withdrawal without medical reason'	Yes 🗸	<b>*</b> °Z	Dialysis withdrawal without medical reason
Sehgal et al., 1996 (USA, Germany, Japan) <sup>128</sup>	Not specified				Not specified	Ď	Dialysis withdrawal defined as per treating nephrologist
Cohen et al., 2000 (USA & Canada) <sup>44</sup>	Yes 🗸	Not specified	D		Not specified	D.	Dialysis withdrawal defined as any patient had stopped maintenance dialysis treatment
Birmele et al., 2004 (France) <sup>37</sup>	Yes 🗸	<b>≻</b> se <b>≻</b>	Yes 🗸	No <b>x</b> Psychosocial reasons for dialysis withdrawal collected, but no patient withdrew due to mental health, financial limitations, or lack of social supports	<b>≻</b> se <b>≻</b>	<b>*</b> ° Z	Death after dialysis withdrawal was defined as death occurred >3 days after last haemodialysis session or >7 days after last peritoneal dialysis procedure
Ko et al., 2019 (USA) <sup>38</sup>	Not specified				Yes 🗸	× ° Z	Dialysis withdrawal defined as 'cessation of follow-up due to discontinuation of dialysis' or 'death due to dialysis withdrawal/uraemia'

Single-centre studies									
Neu & Kjellstrand, 1986 (USA) <sup>1</sup>	Not specified						Yes 🗸	<b>*</b> ° Z	Death after dialysis withdrawal was defined as death occurred >3 days after last session
Hirsch 1989 (Canada) <sup>39</sup>	Yes 🗸 As per medical decision	ision	Yes 🗸	<b>*</b>	<b>*</b> °	× °Z	Yes 🗸	× ° Z	Dialysis withdrawal defined as death due to uraemia or its complications Termination could be requested by the patient, family, or physician
Mailloux et al 1993 (USA) <sup>40</sup>	Yes 🗸	× o Z	No <b>x</b> Quality of life	e was repor	ted as a preci	No ★ Quality of life was reported as a precipitating factor	Yes 🗸	<b>*</b> ° Z	Dialysis withdrawal defined as 'death with manifestations of uraemia because of withdrawal from dialysis.

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	Reasons for dialysis withdrawal	sis withdrav	val				Cause of death	ath	
	Medical reasons		Psychosocial reasons	l reasons					
Literature	Comorbid conditions	Dialysis access	Patient request	Mental health	Financial limitations	Lack of social supports	Kidney failure	Comorbid	Definition
									Underlying medical conditions should not have been active, leading to rapid deterioration with imminent death'
Bordenaveet al., 1998 (USA) <sup>140</sup>	Not specified						Not specified	ō	Dialysis withdrawal defined as any patients stopping dialysis prior to death
Urban & Brennan, 2013 (Australia) <sup>41</sup>	Yes <b>√</b> As per medical decision	scision	Not specified	TO.			<b>&gt;</b> sa <b>/</b>	<b>*</b> °	Dialysis withdrawal occurred when 'patients who had had enough of the dialysis process or where it was felt by the patient, family, or medical team that continuing to prolong life by [dialysis] was inappropriate or undesirable'  Death after dialysis withdrawal was defined as death occurring after stopping dialysis with evidence of death due to a complication of kidney failure.
Chen et al., 2018 (USA) <sup>42</sup>	Yes 🗸 As per medical decision	ecision	<b>√</b> es <b>∕</b>	Not specified	ъ		Yes Y	<b>*</b> ° Z	Dialysis withdrawal defined as permanent stopping of haemodialysis by the patient, family, health care power of attorney, or health care team  Death after dialysis withdrawal defined as death event occurring >24 h after withdrawal

Note: Green: yes; Red: no; and Yellow: not specified.

address the deficiencies in the understanding of the processes of dialysis withdrawal, especially in MICs and LICs.<sup>6,45,47</sup>

## 2.3 | Global variations in dialysis initiation and withdrawal

A prerequisite for dialysis withdrawal is dialysis initiation. The incidence and prevalence of treated kidney failure patients vary widely between countries. 11,13,48,49 The estimated prevalence rates of patients on dialysis in 2010 was much higher in HICs (1064 per million people [pmp]) compared to LICs (16 pmp)<sup>48</sup> (Figure 3A). The incidence of KRT increased significantly in the decade between 2000 and 2013 in MICs, ranging from two to three times increase in the Philippines and Malaysia to over 10 times increase in Thailand. 11,12 However, dialysis funding is only offered for a finite period in some of these countries, resulting in a high attrition rate and disproportionally low prevalence of patients receiving dialysis. 11,50 For instance, the Philippine Health Insurance expanded dialysis coverage from 90 sessions to 144 sessions per year recently in 2021.51 Out-of-pocket expenses are high in MICs and LICs compared to HICs. 13 The annual cost of dialysis care exceeds \$13 000 per person in MICs and LICs and over \$39 000 per person in HICs.<sup>52</sup> Providing long-term maintenance dialysis can be problematic. A systematic review showed over 80% of adult incident dialysis patients in eight sub-Saharan African countries discontinued dialysis, with a mean of 6.5 dialysis sessions.<sup>53</sup> In South Africa, rationing dialysis is a common practice with eligibility for kidney transplantation a critical criterion for dialysis initiation and continuation. 14 Withdrawal decisions are often guided by financial constraints, which are unlikely to change in the

foreseeable future due to economic inequality. Nevertheless, once the decision of dialysis withdrawal is made, the care for the choice-restricted withdrawal process should remain the same as choice-driven dialysis withdrawal with focuses on symptom management and quality of life, taking into account the limited healthcare recourses for end-of-life care.<sup>54</sup>

According to registry data in HICs, up to 30% of adult dialysis patients in North America, Western Europe, and Oceania currently die from dialysis withdrawal.<sup>2–4,32</sup> The proportion of dialysis withdrawal almost doubled between 1995 and 2010 but plateaued over the past decade, despite the rising incidence/prevalence of kidney failure, which may reflect a higher uptake of withholding dialysis in patients with kidney failure.<sup>26,27,29</sup> In MICs and LICs, registry data on dialysis withdrawal are not available.<sup>55,56</sup> Systemic data collection in these countries will provide further insights into potential barriers for dialysis withdrawal in culturally and socioeconomically diverse population groups. When collecting data, further clarification is required to differentiate choice-driven and choice-restricted dialysis withdrawal.

# 3 | BARRIERS TO DECISION OF DIALYSIS WITHDRAWAL

Dialysis withdrawal consists of two components: the initial decision-making process and the subsequent care around the time of dialysis withdrawal. Figure 2 outlines the decision-making process for choice-driven dialysis withdrawal. Numerous barriers currently exist in the process and can be further categorized according to personal preference, cultural and religious beliefs, ethico-legal concerns, and policy-making priorities.

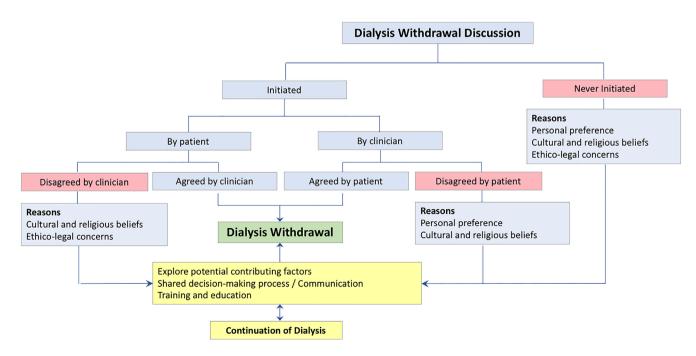
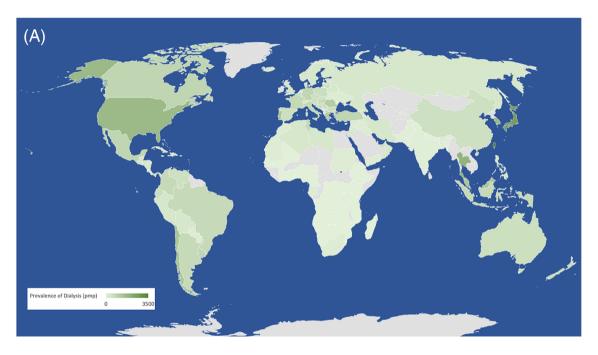


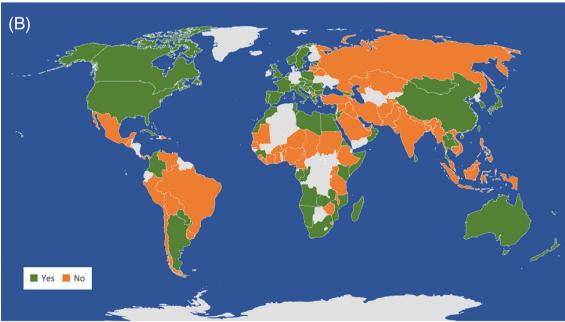
FIGURE 2 Dialysis withdrawal decision-making process for choice-driven dialysis withdrawal

### 3.1 | Personal preference

The willingness of dialysis withdrawal often differs between the patients, carers, dialysis nurses, and clinicians. <sup>57–59</sup> Disagreement may occur when the treating clinician believes dialysis is futile, but the patient and family prefer continuation of dialysis for lifestyle choices, financial attachments, or fear of death. <sup>60</sup> Conversely, the treating clinician may focus on the survival benefits of dialysis when the patient and family prefer quality of life over quantity. Many clinicians still feel

uncomfortable openly addressing dialysis withdrawal when strong emotions are attached to the life-and-death decisions. <sup>57,61</sup> Communication skills specific to dialysis withdrawal are not part of the routine nephrology training. <sup>62,63</sup> Even within the healthcare team, notable discrepancy has been observed. In a Dialysis Outcomes and Practice Patterns (DOPPS) study including six HICs, medical directors were more likely to support dialysis withdrawal compared to nurse managers, and units where medical directors did not encourage dialysis withdrawal had a lower rate of withdrawal (0.8 vs. 1.4 withdrawals/100 patient-





**FIGURE 3** (A) Global prevalence of patients on dialysis (expressed as per million population [pmp]). Data extracted from the 2020 United States Renal Data System (USRDS) Annual Data Report<sup>2</sup> and 2019 Global Kidney Health Atlas.<sup>10</sup> (B) Global availability of choice-driven conservative kidney management. Data extracted from 2019 Global Kidney Health Atlas.<sup>10</sup>

years). As the decision of dialysis withdrawal is often multifaceted with competing factors, similar discrepancies are likely to be observed in MICs and LICs. Acknowledging and addressing personal beliefs of all stakeholders through the shared decision-making process is conducive to successful implementation of dialysis withdrawal. 45,64

### 3.2 | Cultural and religious beliefs

The current dialysis withdrawal literature and guidelines are mostly published from Western countries with a patient-centred focus. Replicating step-by-step recommendations from the guidelines may be culturally or religiously inappropriate in certain populations. In many Asian countries, the decision-making process is family-centred rather than patient-centred. Family may not want open disclosure to the patient regarding treatment prognosis, which violates the foundation of informed consent for dialysis withdrawal. Moreover, the patient may want the family to reach an agreement before the final decision is confirmed; yet, conflicting opinions may exist within family, precluding smooth and timely transition to dialysis withdrawal. Tearly involvement of the family in the discussion of dialysis withdrawal can provide additional time to address concerns related to dialysis withdrawal. As family members may live far away, using telemedicine or virtual meeting is an alternative to face-to-face conversation.

In most religions, there is no explicit law that prohibits dialysis withdrawal. However, conversations about dialysis withdrawal are often extrapolated from religious beliefs on death, which may be a sensitive topic requiring specific communication skills and carefully structured language. A component of avoiding end-of-life discussion is the fear of abandonment and fear of death. However, with the availability of kidney supportive care (KSC)/palliative care, dialysis withdrawal may be considered as a 'good death'. A Patients should be made aware of such support early in the conversation. Most cultures and religions also have a preferred place of death, and home is often the desired option. Elective withdrawal from dialysis is an opportunity for patients to be closer to family and friends in the last days of life with preferred pastoral care.

### 3.3 | Ethico-legal barriers

The impediment relating to the ethico-legal barriers in dialysis with-drawal often varies according to the clinical scenarios. Based on non-maleficence, dialysis withdrawal is deemed appropriate when dialysis results in high symptom burden without significant survival benefits. 20,75-77 However, quality of life and symptom burden are subjective and may be modifiable, which can affect the acceptable level of harms from dialysis. One may argue that clinicians should respect patient's autonomy to continue or discontinue dialysis. Nonetheless, autonomy alone does not override other ethical principles, and competency assessment may be required before the decision can be considered valid. Balancing harms and benefits from dialysis is difficult, and the decision needs to be individualized.

Due to its elective nature, dialysis withdrawal is often erroneously considered as a form of euthanasia, or voluntary assisted dying. However, it must be recognized that dialysis withdrawal is not identical to euthanasia. The cause of death for euthanasia is the medication administered to terminate life; whereas kidney failure is directly responsible for death from dialysis withdrawal, which allows the condition to take its natural course and does not accelerate death.<sup>78</sup> Dialysis withdrawal is considered legal in most countries, including those where euthanasia is not legalized.<sup>79</sup>

Nonetheless, lawful justifications for withdrawal for psychosocial reasons remain controversial and are often based on verdicts of previous legal cases in individual countries. Bo.81 For instance, only medical withdrawal is supported in Japan when dialysis cannot be performed safely or when the patient has extremely poor medical condition. There is no legal regulation regarding psychosocial withdrawal when the medical condition is not terminal. Even when dialysis withdrawal is legally justified, the treating clinicians may not be aware of the laws and may be reluctant to discontinue dialysis owing to the perceived risk of legal consequences. A European survey study showed only 33% of 528 nephrologists who participated in the survey were aware of an explicit law or official regulation for palliative care. Raising medicolegal awareness in the nephrology community may reduce legal misunderstanding in dialysis withdrawal dilemmas.

### 3.4 | Healthcare priorities

In addition to the diverse perceptions of different stakeholders involved in dialysis withdrawal, national policies can also affect the decision-making process. The 2019 Global Kidney Health Atlas showed that despite over 80% of 154 countries worldwide having CKM available, a third had the service easily accessible, and a quarter had training specifically for CKM<sup>85</sup> (Figure 3B). A European survey showed the occurrence of dialysis withdrawal almost doubled when palliative care was reimbursed (OR 1.81, 95% CI 1.16–2.83), suggesting clinicians are willing to proceed with dialysis withdrawal when appropriate conservative care is provided.<sup>83</sup> The International Society of Nephrology has incorporated CKM in the Strategic Plan for Integrated Care of Patients with Kidney Failure for the next 5–10 years.<sup>55</sup>

In MICs where the incidence of dialysis is rising, the healthcare priorities tend to focus on promoting equity for dialysis access instead of advocating dialysis withdrawal, similar to the pattern observed in HICs in the 1960s and 1970s. <sup>86</sup> Considering dialysis is a costly treatment with significant health-economic burden, incorporating policies and funding for CKM (including dialysis withdrawal) into routine kidney failure management could broaden the treatment options with potential health-economic benefits while maintaining high quality of healthcare. <sup>13,50,54,87</sup> However, it is important to emphasize that CKM and dialysis withdrawal should not be considered as a cost-saving strategy, and dialysis should be offered to patients with tangible clinical benefits in a well-resourced healthcare system. <sup>88</sup>

# 4 | DIALYSIS WITHDRAWAL DURING COVID-19 PANDEMIC

Since 2020, the COVID-19 pandemic has affected the delivery of healthcare globally, including the process of dialysis withdrawal. Social isolation and travel restrictions have complicated the already difficult dialysis withdrawal process attributed to interrupted engagement with healthcare system, lack of immediate family support, and limited endof-life care options in fear of potential infection risks.<sup>89,90</sup> For patients with COVID-19 infection and related acute kidney injury, allocation or redeployment of scarce healthcare resources has resulted in rationing policies and involuntary dialysis withdrawal, even in HICs where rationing medical resources was considered unacceptable previously. 91,92 Although some have argued that such practice violates individual ethics, policymakers and medical communities have published decision-making guidelines supporting utilitarianism to maximize total benefits, 93-95 similar to choice-restricted dialysis withdrawal in MICs and LICs. 96,97 Implementing strategies to address additional barriers while maintaining the balance between ethical dilemmas, government policies, and clinical practice remains a challenging lesson during the COVID-19 pandemic.

# 5 | IMPLEMENTATION OF DIALYSIS WITHDRAWAL

Implementing dialysis withdrawal is often complex, involving multiple stakeholders, lengthy discussions, and heightened emotions. There is no standardized pathway that accommodates a multitude of clinical situations. Incorporating KSC into routine nephrology practice can assist in overcoming potential barriers for dialysis withdrawal.<sup>9,45</sup>

### 5.1 | Kidney supportive care

KSC is an evolving subspecialty in nephrology that incorporates principles of palliative care and has expanded from comprehensive CKM for patients on the conservative, non-dialysis pathway to holistic care on patient-centred symptom management and quality of life improvement in patients with kidney disease, including patients on dialysis and subsequent dialysis withdrawal.<sup>98</sup> An ideal program encompasses a multidisciplinary team and may comprise physicians, nurses, dietitians, social workers, physiotherapists, chaplains, and psychologists/psychiatrists. 98,99 KSC services complement primary nephrology care. The service delivery may be led by palliative care physicians, nephrologists, or other healthcare professionals with additional training in palliative care. The last is more commonly seen in resource-limited areas. 100 Ongoing involvement of the primary nephrologist is essential as patients often rely on the opinions of their treating nephrologist to guide the dialysis withdrawal process.<sup>7,62</sup> An interview report of 17 KSC programs in HICs showed a successful program consists of adequate provider training (especially in communication), close collaboration between palliative care and nephrology, dedicated champions, and evidence-based education

with national guidelines.<sup>8</sup> We present a theoretical dialysis withdrawal pathway with potential strategies using key elements of KSC, highlighting gaps in the current guideline recommendations (Figure 4, Table 2).

### 5.2 | Decision of dialysis withdrawal

### 5.2.1 | Identifying appropriate patients

Both the RPA-ASN and KDIGO guidelines suggested dialysis withdrawal to be considered in patients with very poor prognosis, when dialysis cannot be provided safely or when patients opt to discontinue dialvsis with informed consent via advance care planning (ACP) or appointed legal guardian.<sup>6,45</sup> Factors associated with dialysis withdrawal include older age, underweight, late nephrology referral, haemodialysis via central venous catheter, presence of comorbid conditions, and poor quality of life. 22-24,29,33,42 The reported risk factors may represent overall frailty of the patient group, 28,101,102 and integrating frailty assessment in the decision-making process likely provides a more objective prognostic evaluation instead of a single risk factor. Multiple studies are currently underway to identify a validated prognostic assessment tool or frailty index specifically for patients receiving dialysis. 88,103,104 Identifying the appropriate patients early and delivering open discussion pertaining to dialysis withdrawal provide additional time for patients to process the information and have autonomy over the decision relating to the life-and-death situation. Furthermore, some of the medical and psychosocial burdens may be modifiable, and addressing these issues early may avoid the need for dialysis withdrawal. 42,54,105 Clinicians need to overcome the fear of selecting the 'wrong' patients for dialysis withdrawal as a singletimepoint decision and to re-evaluate the appropriateness of dialysis withdrawal through ongoing conversation in multiple clinical settings via the shared decision-making process.

### 5.2.2 | Shared decision-making process

As the decision of dialysis withdrawal is subjective, dialysis withdrawal guidelines uniformly recommended using the shared decision-making process to obtain informed consent, conduct ACP, and facilitate dialysis withdrawal. 6.45.47.64.82 The process involves a collaborative discussion between the multidisciplinary team and the patient to identify mutual goals and the process to achieve these goals, which is especially important when disagreement occurs between stakeholders. 106 Local legal regulations acknowledging and justifying the shared decision-making process can provide an additional layer of protection for clinicians and patients. 80

Specific communication skills are required to address heightened emotions and to resolve conflicts during the shared decision-making process. 107,108 Serious illness conversation workshops through established palliative care programs or Nephrotalk (using tools such as NURSE [naming, understanding, respecting, supporting, and exploring]) are valuable for difficult situations like dialysis

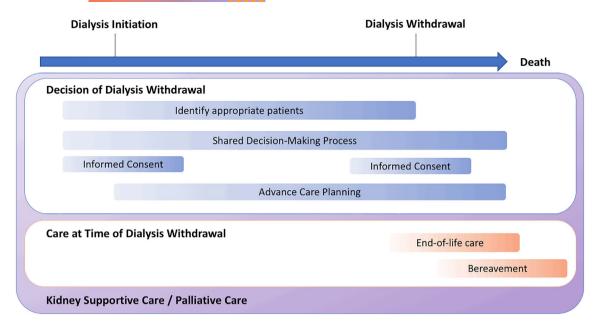


FIGURE 4 Proposed implementation process for dialysis withdrawal using key elements of kidney supportive care

**TABLE 2** Kidney supportive care elements in dialysis withdrawal

	Pros	Cons	Limitations
Identifying appropriate patients	<ul> <li>Early intervention</li> <li>Ability to correct modifiable concerns and, possibly, avoid dialysis withdrawal</li> </ul>	<ul> <li>Risk of identifying the 'wrong' patients</li> </ul>	<ul> <li>Uncertain prognosis</li> <li>Lack of a single assessment tool to identify the appropriate patients</li> </ul>
Shared decision- making process	<ul><li>Patient-oriented care</li><li>Holistic approach</li></ul>	Time constrains	<ul><li>Lack of training for healthcare professionals</li><li>Language barriers</li></ul>
Informed consent	Respect patient's autonomy	Time constrains	<ul> <li>Patients without capacity or poor health literacy</li> <li>Language barriers</li> <li>Timing of informed consent</li> </ul>
Advance care planning	Provide guidance when a patient loses capacity to make decisions	<ul><li> Time constrains</li><li> Lack of centralized information sharing system</li></ul>	<ul><li>Potential change of mind</li><li>Language barriers</li></ul>
End-of-life care/ bereavement	<ul><li>Symptom management</li><li>Avoid 'abandonment' after dialysis withdrawal</li></ul>	Additional healthcare resources	<ul> <li>Lack of culturally/religiously appropriate service</li> </ul>

withdrawal.<sup>63,109,110</sup> These workshops have been reported to improve preparedness and empathy for serious illness conversations during simulation sessions.<sup>63,109</sup> The benefits in real-world practice remain unclear as systematic reviews showed high heterogeneity between randomized controlled trials and poor methodology in the majority of the qualitative studies without controlled or randomized participants.<sup>111,112</sup> Poor health literacy and language barrier are major modifiable barriers in the shared decision-making process, especially in countries like India where thousands of dialects are spoken. Communication skills for serious illness conversations alone do not address these challenges when the conversations are lost in translation, resulting in decisions being made based on incorrect assumptions. A culturally sensitive team with local champions is preferred.<sup>113,114</sup>

Using visual and audio aids and printed education materials for selected patients may improve health literacy. <sup>115</sup>

### 5.2.3 | Informed consent

One of the earliest opportunities to discuss dialysis withdrawal is when obtaining informed consent for dialysis initiation. Informed consent entails three major components: competency, voluntary decision, and provision of sufficient information. <sup>116</sup> Unfortunately, informed consent for dialysis is often poorly conducted, especially in patients initiated on acute dialysis when discussion of the intricate details of dialysis withdrawal is omitted due to insufficient time or inappropriate setting. <sup>117,118</sup>

When obtaining informed consent just prior to dialysis withdrawal, patients may also have cognitive impairment from dementia, medication overdose, depression, or uraemia. Guidelines have recommended a surrogate decision-maker or legal guardian when the patient fails to make competent decisions. However, such processes may be lengthy, resulting in the reluctance to initiate the serious illness conversation.

Besides the conventional dialysis pathway, time-limited dialysis and palliative dialysis approaches are alternative options when obtaining informed consent for dialysis initiation, which may be practical in facilitating future dialysis withdrawal. Time-limited trial refers to conventional dialysis for a finite period, which can take place when the prognosis of comorbid conditions is uncertain. In contrast, palliative dialysis provides symptom relief without focusing on rigid dialysis schedules or biochemical targets. However, dialysis withdrawal is often more difficult than withholding dialysis as patients and families may believe dialysis withdrawal hastens death when end-of-life is imminent.

### 5.2.4 | Advance care planning

ACP utilizes shared decision-making process to enhance patient's understanding of prognosis and treatment options, provide guidance to future treatment based on individual priorities, and minimize emotional and financial burdens by avoiding futile or undesirable medical treatment. 123 As patient's preferences may change when social or clinical circumstances change, ACP should be a continuous and dynamic process with re-evaluation during major changes of management plans, symptoms deterioration, functional decline, prolonged hospital admissions, or social distress. 47,123-125 Written advance care directive is only a part of the process that formalize patient's wishes. It is considered a legally binding document in some countries but can be overridden by family or treating clinicians in other countries. 124,126 For patients on dialysis, the ACP should include accepted reasons for dialysis withdrawal, surrogate decision-maker, and preferred place of death. 127 Unfortunately, ACP and advance care directives are underutilized and are often incomplete due to inadequate skills, time pressure during routine care, and lack of legal understanding of the process.7,127-129 Furthermore, a universal health record sharing system is often lacking, and ACP may not be followed through. 130 A formalized system with target key performance indices may increase the utilization of ACP and ensure patient-centred care during the dialysis withdrawal process.

### 5.3 | Care at time of dialysis withdrawal

### 5.3.1 | End-of-life care

The average time to death following dialysis withdrawal is approximately 10 days, but may extend up to 3 weeks in patients with residual kidney function.<sup>131</sup> During this period, the patient may have high

symptom burden including pain, uraemic pruritus, confusion, dyspnoea, nausea, and associated emotional distress. Evidence-based KSC treatments are available to alleviate these symptoms, <sup>98,132–134</sup> and the multidisciplinary team can provide additional psychosocial supports for the patient and family before and during the withdrawal process. Due to the elective nature of dialysis withdrawal, pastoral care through the local community can be arranged to relieve existential distress. End-of-life care can take place within the hospital, hospice, or at home. <sup>135</sup> As end-of-life care in hospice and at home is well-established for patients with cancer, additional education tailored to kidney failure may be required in these settings.

### 5.3.2 | Bereavement support

The continuity of KSC extends beyond death. Bereavement support for family members and friends after the patient's death can minimize complex or disenfranchised grief reactions. With the long-term relationship between patients, their family members, and the dialysis healthcare professionals, a culturally sensitive memorial service organized through KSC offers closure to everyone involved and has been an annual tradition in many kidney care units. However, with multiculturalism, it may be challenging for the kidney care units to tailor the memorial service for all families and carers. Linkage with and utilization of community pastoral care could provide additional support and culturally appropriate guidance.

### 6 | CONCLUSION

Dialysis withdrawal is an accepted treatment option for patients with kidney failure, but it is a complex process with clear differences in the understanding, awareness, acceptance, and uptake within and between countries. Changes at individual, hospital, and government levels are required to improve the acceptance and quality of dialysis withdrawal. One of the main challenges is the lack of a clear and consistent definition of dialysis withdrawal; therefore, inferences drawn from the studies reporting on the processes and outcomes of dialysis withdrawal are limited and typically not generalisable. Even though the principles of dialysis withdrawal and its implementation are similar between countries, local guidelines will need to be pragmatic and adaptable according to country-specific resource availability, while ensuring cultural, religious, and spiritual appropriateness. Urgent actions focusing on establishing CKM programs and centralized data collection on local dialysis withdrawal experience are essential to facilitate the implementation of dialysis withdrawal and to understand the current clinical practice. These changes will have significant implications on the decision-making process, legal consequences, and healthcare funding and policies for dialysis withdrawal.

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