

The Ethics of Chronic Dialysis for the Older Patient: Time to Reevaluate the Norms

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Abstract

Recent research highlights the potential burdens of hemodialysis for older patients with significant comorbidities, for whom there is clinical equipoise regarding the net benefits. With the advent of accountable care and bundled payment, previous incentives to offer hemodialysis to as many patients as possible are being replaced with a disincentive to dialyze high-risk patients. While this may offset the harm of overtreatment for some elderly patients, some voice concerns that the pendulum will swing too far back, with a return to ageist rationing of hemodialysis. Nephrologists should ensure that the patient's rights to be informed about the potential benefits and burdens of hemodialysis are respected, particularly because age, functional status, nutritional status, and comorbidities affect the net balance between benefits and burdens. Nephrologists are also called on to help patients make a decision, for which the patient's goals of care guide determination of potential benefit from hemodialysis. This article addresses concerns about present overtreatment and future risk of undertreatment of older adults with ESRD. It also discusses ways in which providers can ethically approach the question of initiation of hemodialysis in the elderly patient by including patient-specific estimates of prognosis, shared decision-making, and the use of specialist palliative care clinicians or ethics consultants for complex cases.

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Introduction

Moral and technological imperatives to treat patients irrespective of age and prognosis (1), coupled with a push for earlier dialysis start, have disproportionately affected patients older than age 75 years (2). These trends resulted in a 57% age-adjusted increase in dialysis for octogenarians and nonagenarians in the United States between 1996 and 2003 (3). During the past decade increasing evidence has suggested that the overall benefit of dialysis is modest at best for certain populations, including frail, elderly patients with multimorbidity (4–6). We have argued that the current practice of dialysis in frail elderly patients often violates the four core principles of bioethics: respect for autonomy, beneficence, nonmaleficence, and justice (7). We concluded that a narrow interpretation of beneficence that focuses only on life extension fails to consider that many elderly patients have other goals and priorities that are equally if not more important to them (7,8). Although major professional societies (9,10) and the Institute of Medicine (11) recommend that patients' goals and values be used to guide treatment recommendations (10), this is not consistently done, particularly for high-risk or frail elderly patients (1,7,12–16).

Globally, aging demographics coupled with a growing technological imperative to treat at advancing ages are straining health care resources. Dialysis is a costly treatment that historically has been subject to rationing (17,18) but is also used as a benchmark for societal willingness to pay for medical care (19). In the United States, bundling of Medicare reimbursement for ESRD management may have a profound effect on clinical

recommendations for dialysis. The prospect of a return to rationing care for this vulnerable population is worrisome (7,20).

In this article, we address both concerns of overtreatment and possible future undertreatment of the frail elderly patient with ESRD. We also discuss ways in which nephrologists and other providers can ethically approach the question of initiation of dialysis in the elderly patient *via* a process of shared decision-making.

Preserving Patient Autonomy

Respect for patient autonomy is a cornerstone of health care in the United States that courts have consistently upheld (21). To be truly autonomous, patients must be fully informed and able to understand their options and the likely implications of their choices (10). Many patients receiving hemodialysis express a desire to know their treatment options, as well as their prognosis (13). Surveys and interviews of patients undergoing hemodialysis suggest that most patients believe they were not given sufficient information, or other viable choices, on their ESRD and hemodialysis (1,12–16). We believe that this needs to change and that regular, iterative exploration of patients' goals of care can effect this change. Ideally, this should begin well before the need for dialysis is urgent so that patients have time to reflect on their goals, values, and preferences. The hope is that this would mitigate the sense of urgency and lack of autonomy some patients report (12,16). Patients can have many goals of care. Kaldjian *et al.* have identified six commonly discussed goals that should be

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Table 1. Six commonly articulated goals of care

1. Be cured
2. Live longer
3. Improve or maintain function/quality of life/independence
4. Be comfortable
5. Achieve life goals
6. Provide support for family/caregiver

Adapted from reference 8, with permission.

explored with patients facing CKD (Table 1) to allow them to articulate which treatments will help them accomplish their goals (8).

The first key question a patient with moderate to severe CKD faces is “How likely is it that I am going to need dialysis?” Population-based studies have shown that patients with CKD (even advanced), especially elderly patients, are more likely to die of other comorbidities than to need dialysis (22,23). Tangri *et al.* have developed a model using routinely available laboratory tests that accurately predict progression to ESRD in patients with CKD stages 3–5 (24). Working through this with patients is especially important because evidence suggests that an intention to defer hemodialysis may be in patients’ best interest (25). Once individualized risk has been established, patients and their providers should actively manage this risk so as to prevent AKI and progression of CKD to ESRD.

Once a patient has progressed to ESRD and hemodialysis seems clinically inevitable, the question becomes “How much extra time will hemodialysis buy me and what are the benefits and harms of treatment?” Clinical equipoise regarding this exists because no evidence is available to determine whether hemodialysis is more often helpful or harmful for frail elderly patients with significant comorbidities (5,26,27). Prognostication in this situation is also more challenging as the stakes are higher and existing tools may not discriminate well for individuals, especially elderly patients with multimorbidity (28). Best prognostic estimates can still help inform the discussion, but the degree of uncertainty of such assessments must be made clear to the patient and family. If the prognosis is guarded and dialysis will be a destination therapy, a more palliative approach to care is appropriate (29).

In discussing options with patients, it is critically important to avoid presenting treatment option as binary (“Do hemodialysis or do ‘nothing’”) or worse (“Do hemodialysis or die”). Deliberations should include the full spectrum of treatment options, including in-center hemodialysis, home hemodialysis, peritoneal dialysis, low-protein diet, the possibility of living donor transplantation, and maximum medical management without hemodialysis (*e.g.*, palliative care and hospice). Indeed, living-donor kidney transplantation can be a viable option, even for elderly patients, if they meet set criteria (30). Peritoneal dialysis is an acceptable alternative to in-center hemodialysis in terms of survival (31), satisfaction (32), and improved quality of life for many elderly patients (33). Initiation of hemodialysis can sometimes be delayed by a very-low-protein diet, and an Italian study achieved an average delay for hemodialysis commencement

of 10.9 months (34). Palliative care without hemodialysis can also achieve good quality of life, although the evidence is insufficient to determine whether hemodialysis or conservative care is superior for the frail elderly patient (5). Frailty is extremely common among patients receiving hemodialysis in the United States (35) and is associated with early dialysis start and high mortality rates (36). For patients who are most frail or have multiple comorbidities, determining frailty *via* available tools, such as the FRAIL (Fatigue, Resistance, Ambulation, Illnesses, and Loss of Weight) (37) or Rockwood (38) index, can help address the optimism bias often encountered in patients and families with critical illness; in turn, unrealistic expectations regarding treatment benefits can be avoided (39,40). Best case/worst case scenarios can be helpful for patients and families to more accurately appreciate a full spectrum of possible outcomes. For the sickest patients, a validated online risk calculator can help determine whether the patient qualifies for the Medicare hospice benefit based on their kidney failure (<http://www.qxmd.com/calculate-online/nephrology/predicting-6-month-mortality-on-hemodialysis>) (41).

Beneficence and Nonmaleficence Need to Be Viewed through the Patient’s Lens

Patients undergoing hemodialysis often experience a high treatment and symptom burden that is often not properly recognized and treated (42–44). The Hippocratic Oath emphasizes nonmaleficence as a central goal of medicine. Many health care providers are driven by a strong desire for beneficence, which Pellegrino and Thomasma have also emphasized as the central aim of medicine (45). However, in weighing the benefits and burdens of treatments, what someone views as beneficence another may see as maleficence, depending on the patient’s goals and values. In our current system, inexorable momentum toward seeking care that extends life is the norm (46,47). Physicians have even reported agreeing with families against a patient’s expressed wishes when the family member’s goals are more aggressive than those of the patient (48,49). This can be viewed as a failure to respect patient autonomy, or even maleficence if the treatment burden is significant. A narrow definition of beneficence, focused on preserving and extending life, is a major driver of the moral imperative to treat (7). While many patients have living longer as one of their goals of care, it was the main or central goal for only a minority of people in a study of hospitalized patients—while goals such as functionality weighed heavier for many patients (50). Beneficence and nonmaleficence should be judged from the purview of the patient. Physicians and other health care providers bring personal values and biases that can shape the approach to how difficult treatment discussions are broached (51). They are also influenced by incentives such as reimbursement adjustments based on process and quality metrics (29,52). It is important for clinicians to recognize and set aside those agendas to meet the needs of the patient and/or their surrogate(s).

Without doubt, dialysis is a valuable, life-extending treatment that has enabled thousands of patients with ESRD to live longer with improved quality of life. Dialysis remains an appropriate and beneficial treatment for the highly functional elderly person for whom transplant is not an

option or is not desired. That being said, it remains important not to rush to initiating dialysis. Several recent studies have highlighted the lack of benefit and potential harm from earlier initiation of dialysis, and this also pertains to the elderly patient (25,53). Frailty increases the risk of earlier dialysis start (36). Canadian guidelines now recommend intention-to-defer dialysis (25). This is especially important for the oldest patients because one third of octogenarians with advanced CKD do not progress to ESRD and require only observation and conservative management (54).

A major drawback with lack of optimal preparation for hemodialysis relates to vascular access issues, in particular, maturity of a permanent access (*i.e.*, arteriovenous fistula). Those concerns must be weighed against the harm of placing fistulas in people who are never going to need them (55) and that may never mature (56). In addition, the presence of a mature fistula appears to be associated with a lower threshold to initiate hemodialysis (57). Patients can follow variable trajectories with CKD, which can help inform the transition point from observation to hemodialysis preparation (58). Also, the calculator for risk of progression of CKD to ESRD can help determine timing (24). Too strict an adherence to guideline-based care and quality metrics without discrimination by clinical status and goals of care can hinder a more nuanced and patient-centered approach to care (29,52,59).

Some patients do not tolerate in-center hemodialysis well and have suboptimal quality of life, or even harm from the treatment. Qualitative studies have uncovered a significant symptom and treatment burden associated with hemodialysis (43,60). Elderly patients undergoing hemodialysis frequently experience rapid loss of functional status (61) and independence once hemodialysis is initiated. Independence remains a central goal for many patients (50). Despite specific Medicare coverage, hemodialysis is still a costly treatment, and financial implications need to be taken into account when considering nonmaleficence (62). Hospice services are underused in this patient population despite a mortality and symptom burden rivaling that of many patients with cancer (63,64). This is true even for patients who choose to discontinue hemodialysis (65). Finally, patients undergoing hemodialysis receive more intensive and potentially intrusive end-of-life care compared with patients with other life-limiting conditions (63). It is worrisome that these patients may be deprived of the potential benefits of aggressive symptom control with noninvasive measures to promote better quality of life near the end of life.

All these factors must be considered when discussing options with a patient facing initiation of dialysis so that the individual can weigh the benefits and harms of the treatment plan and how the plan fits goals of care. For patients ambivalent about how to proceed, a time-limited trial of hemodialysis or other dialysis modalities with *a priori* definition of measures of success or failure is a reasonable approach. In a survey of patients undergoing hemodialysis and their surrogates, three quarters of surrogates viewed a time-limited trial of hemodialysis positively when faced with uncertainty about outcomes (66). It is also important to emphasize that stopping dialysis and not starting dialysis are morally, ethically, and legally equivalent (10). Nephrologists, patients, and families need not feel moral distress when stopping

dialysis to honor the wishes of patients or their surrogates. Clinicians may have a conscientious objection to discontinuing dialysis; thus, multidisciplinary care is ideal for promoting patient-centered outcomes (10).

Shared Decision-Making as an Answer to the Ethical Challenges

Shared decision making around hemodialysis initiation and discontinuation can ensure fidelity to the first three principles of bioethics: respect for autonomy, beneficence, and nonmaleficence. Once key goals have been identified, patients often need help weighing their options to help them achieve their most important goals (59). There are, however, several challenges to true informed consent and shared decision-making. First, nephrologists and nephrology fellows have reported that they feel ill-prepared to have these discussions (67,68). Second, physicians often bring their biases to the bedside, which can affect the patients' perception and ultimate decision (51,69). Finally, patients and family members of seriously ill patients tend to have a significant optimism bias when faced with dire prognosis, which may affect their choices as surrogate decision-makers for their loved one (39,40). Shared decision-making that allows a patient's goals to be met as accurately as possible should still be the goal.

In other conditions, decision aids improve patients' knowledge of their options, give them realistic expectations of benefits and harms, and help them make choices concordant with their values and goals of care (70). Patients undergoing dialysis desire to be informed and involved in these discussions (13). Having a choice about which RRT is used can even improve quality of life (71). Despite the paucity of decision aids/tools focusing on dialysis initiation (72), several resources are available to help prepare patients with ESRD and to engage them in shared decision-making. The Renal Physicians Association has recently updated its clinical practice guidelines on shared decision-making—a cornerstone of how to approach challenging clinical decision-making before initiation of dialysis through end of life (10). This resource is now available as an applet for use at the bedside (<https://itunes.apple.com/us/app/rpa-sdm-toolkit/id843971920?mt=8>). Health outcomes prioritization is an approach designed for elderly patients that can help patients weigh their options for health care (73). To address lack of communication skills (10), training is now available through NephroTalk (74). This unique training program focuses on building nephrologists' skills in addressing challenging discussions; it is modeled after another successful program developed to address similar challenges faced by oncologists (74).

Table 2 outlines a stepwise approach to discussions about the initiation and discontinuation of hemodialysis. Ideally, all nephrologists should be able to manage the basics of advance care planning and symptom management because they are treating a patient population with high mortality and symptom burden (75). In especially challenging clinical or psychosocial situations, subspecialty-certified, palliative-care trained clinicians and clinical ethicists can be helpful in moderating difficult discussions. If consensus cannot be reached, it is important to develop a due process (10).

Table 2. Recommended approach to starting and discontinuing hemodialysis in the elderly

1. Assess the patient's goals of care (8,73) and institute advance care planning (10).
2. Assess the patient's risk profile and prognosis (10,24,41).
3. Evaluate the patient's prognosis in the context of his/her goals of care.
4. Communicate individualized treatment options and likely outcomes (best case/worst case) (10).
5. Engage the patient and family in deliberation on treatment choices (10,73).
6. Make individualized treatment recommendations to fit the patient's goals of care if the patient prefers a physician-led decision-making process or if patients or surrogate decision struggle with their choices.
7. Consider recommending against dialysis in patients with very poor prognosis, contraindications, or safety concerns (10).
8. Consider a time-limited trial with predefined milestone measures of success/failure if there is significant ambivalence or lack of consensus. Involve the ethics consult team or use other due process in challenging cases (10).
9. Identify and treat burdensome symptoms and minimize treatment burden (75). Involve specialist palliative care physicians for complex cases (10).
10. Periodically reassess the patient's willingness to continue dialysis as well as hospice eligibility.
11. Enable the patient to opt out of dialysis if continuation is no longer consistent with his/her goals of care.

Justice Challenges during Times of Change

Aging demographics and associated comorbidity are straining health care resources globally. While dialysis has been used as a benchmark for societal willingness to pay for medical care (19), it is a costly treatment that historically has been subject to rationing (17,18). In the United States, the Medicare benefit for ESRD is unique in covering the population for a specific medical treatment for a specific disease (76). This discrimination by diagnosis raises important issues of distributive justice. Social justice is also challenged by policies that enable for-profit hemodialysis vendors to cherry pick patients to maximize profits from public funds (77). With bundling of care, previous incentives to offer hemodialysis to as many patients as possible will be replaced with a disincentive to dialyze high-risk patients. This is concerning because hemodialysis practices are sensitive to financial incentives and cherry picking (78,79). In other countries, dialysis may again become a target for explicit and implicit age-based rationing according to cost and lack of demonstrated benefit (17). While this may offset some harm with overtreatment in elderly patients (4), there is also a risk that the pendulum will swing too far, with a return to ageist rationing of hemodialysis (7,20).

Nephrologists should see this challenge as a unique opportunity for a public debate on how to defend this important societal benefit. Clinicians should engage with patient advocacy groups to come up with patient-centered approaches that meaningfully address the twin traps of overtreatment and therapeutic nihilism (80). The default thinking regarding

treatment options for elderly patients with ESRD needs to change from the technological imperative to dialyze to that of deferring dialysis for as long as possible, and to iteratively engage patients in a process of shared decision making throughout the disease trajectory (5). Ethically transparent approaches to deciding who does or does not commence dialysis are paramount to preserve equitable access to dialysis and prevent a return to implicit rationing (7,10).

We conclude that there is no better way to achieve this goal than to engage patients in shared decision-making as recommended by the American Society of Nephrology (9), the Institute of Medicine (11), and the Renal Physicians Association (10). Nephrologists and intensivists need to collaborate with clinical ethicists and palliative care providers to develop meaningful guidance and training for the clinicians who are helping patients and their families navigate these difficult decisions. We also need to ensure that guidelines and quality metrics allow stratification by clinical status and goals of care so that dialysis providers are not penalized for honoring the wishes of patients whose goals of care are less aggressive, as recommended by the dialysis advisory group of the American Society of Nephrology and others (29,52,59). More research is needed to guide treatment recommendation in this age group, especially frail elderly patients.

Conclusion

Current evidence does not support the moral and technological imperative to dialyze all elderly patients with ESRD—irrespective of comorbidity and functional status. Nephrologists should not default to offering hemodialysis to all elderly patients with ESRD, especially those who are frail or have multiple comorbidities, for whom evidence of benefit is lacking. The elderly patient with ESRD should be presented with treatment options that best fit his or her goals. Depending on the clinical status, this can include hemodialysis, alternative RRT, active medical management without hemodialysis, palliative and hospice care, and living-donor transplantation. Shared decision-making ensures that the ethical principles of autonomy, beneficence, and nonmaleficence are honored as best possible. The process should be based on the best available evidence so that patients and their families can choose the treatment that best fits their values and goals of care. Because of significant risks and burdens associated with hemodialysis in the frail elderly, an intention to defer hemodialysis as long as possible may best protect nonmaleficence. Better evidence on comparative clinical outcomes is needed to guide treatment options for the elderly patient needing dialysis. To counter the risk of return to biased rationing of dialysis and to preserve the Medicare ESRD benefit for future generations, nephrologists and their patients need to engage in processes that safeguard their autonomy and promote fair treatment allocation decisions.

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