

Informing Our Elders About Dialysis: Is an Age-Attuned Approach Warranted?

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Summary

As the fastest growing sector of the incident ESRD population, older patients constitute a group for which renal replacement therapy has special implications. Older CKD patients have unique needs by virtue of advanced age, high prevalence of comorbid conditions, slower progression of renal disease, and reduced survival. Burdens and risks attendant to dialysis may be amplified in the older patient and patients with impaired functional status or comorbid conditions, and therefore, dialysis may confer little to no survival benefit. Rates of dialysis withdrawal are highest among the oldest patients, raising the possibility that the standard content of informed consent for dialysis warrants an age-sensitive approach that is attuned to the very different balance of pros and cons of dialysis for older patients with multiple comorbidities and younger patients with limited comorbidity. Informed consent for older patients should include presentation of risks, benefits, and burdens associated with dialysis, age-specific estimates of prognosis with and without dialysis, and potential for loss of independence and decline in functional status with initiation of dialysis. In this article, medical evidence and clinical practice guidelines relevant to advance care planning for the older patient with CKD are reviewed, issues to consider in the dialogue with older patients contemplating dialysis are presented, and recommendations for an age-attuned approach to informed consent for older CKD patients are made.

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Introduction

An estimated 47% of individuals >70 years of age carry the diagnosis of CKD, and the prevalence in those individuals >80 years of age is even higher (1). The proportion of patients >65 years of age starting dialysis has increased by nearly 10% annually, representing an overall increase of 57% between 1996 and 2003 (2,3). The fastest growing segment of the incident ESRD population (3), elderly patients (defined as individuals >75 years old), have a high prevalence of comorbid conditions (4), with a constellation of risk factors that often overlaps with CKD. Despite notable differences in pathophysiology and the natural history of CKD in older versus younger individuals, clinical guidelines and recommendations are rarely age-specific (5) and do not address issues in the context of the older patient. Traditionally, options for much of medical care have been relegated to a one size fits all approach, although recognition that elderly patients have different needs, values, and perspectives on survival is increasingly apparent. For patients with CKD, the effects of age on progression of renal disease and survival to dialysis are sufficiently profound to prompt the recommendation that nephrologists avoid an age-neutral approach when considering the propriety of dialysis in elders (6). Research over the last decade on end of life care has added greatly to the armamentarium of tools available (Tables 1 and 2) to help nephrologists objectively counsel older patients with CKD (7), although the majority of literature does not focus on the propriety of initiating dialysis but its discontinuation.

With the passage of legislation that assured coverage for dialysis in 1972, responsibility for determining which patients are appropriate for dialysis was delegated to nephrologists, whose ethical responsibility to “first do no harm” is ever challenged by technological and medical advances. Furthermore, as effectiveness and low risk of new procedures such as renal replacement therapy (RRT) promote their incorporation into standard practice, choice is effectively eliminated, fostering what has been referred to as the biomedicalization of death in the elderly (8). Indeed, many older and sicker patients starting dialysis today would have been ineligible before enactment of this legislation, a stark contrast to the current climate where technical success and widespread availability of RRT has blurred the distinction between opportunity to extend life and obligation to do so. The decision to start dialysis is a personal one that is directed by one’s medical condition and motivated by desire to continue or prolong life and by willingness to accept the risks and burdens inherent to this life-sustaining procedure. Reports that many patients regret their decision to start dialysis (9) underscore the importance of advance care planning (ACP) and suggest a need to evaluate processes by which our patients are informed and ultimately, consent to dialysis. In this paper, medical evidence and clinical practices relevant to ACP for the elderly CKD patient are reviewed, and issues that merit consideration in the dialogue with those individuals contemplating dialysis are presented.

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Table 1. Web resources for advance care planning at the end of life

The Kidney End of Life Coalition provides information and resources to help dialysis professionals, facilities, and patients complete advanced care planning and advanced directives (<http://www.kidneyeol.org/>).

The Caring Connections website offers information about advanced care planning and free downloads of state-specific, legal advanced directives (<http://www.caringinfo.org/stateaddownload>).

The Physician Orders for Life-Sustaining Treatment form contains patients' end of life wishes in an easily identifiable, portable format with reviewable medical orders. The form honored throughout the healthcare system is recognized as a preferred practice by the National Quality Forum in its *A National Framework and Preferred Practices for Palliative Care and Hospice Care Quality* (<http://www.polst.org>).

Hemodialysis mortality predictor (<http://touchcalc.com/calculators/sq>) (50).

Table 2. Tools available in the Renal Physicians Association Guideline for Shared Decision Making

Depression assessment
 Cognitive capacity assessment
 Decision-making capacity assessment
 Quality of life and functional status assessment
 Prognosis assessment
 National Kidney Foundation initiation and withdrawal checklists
 Pain and symptom assessment and management
 Communication skills
 Glossary of terms

Impact of Age, Functional Status, Comorbid Medical Conditions, and Dialysis on Survival

The trajectory of illness is variable and unique to CKD, and neither renal failure nor its sequelae is predictably the terminal or even sentinel event. For patients on dialysis, the presence of comorbid conditions is the single most predictive factor of outcome and is additive with age in predicting survival (10–14). Average first year mortality for dialysis patients over the age of 65 years is 46%, with those individuals older than 85 years having 22% greater likelihood of death in the first year (2) and a median survival of 11.6 months compared with 24.9 months for individuals between 66 and 79 years. A high prevalence of frailty has been noted among older patients on dialysis (15), and it is associated with a threefold higher risk of death, supporting a primary role for frailty as a predictor of outcome. Marked functional impairment, a history of falls, and the inability to transfer are other indicators of poor prognosis (16,17) along with hypoalbuminemia, a strong predictor for mortality in patients on dialysis (13,18–20).

Several methods of predicting outcomes in CKD have recently been advanced. A clinical score using nine comorbid conditions to predict 6-month prognosis in patients over 75 years starting dialysis found that individuals with the highest scores had the highest mortality, with rates as high as 70% (21). The surprise question, "Would I be surprised if this patient died in the next 12 months?," has been recognized as a simple and reliable method of identifying sicker incident dialysis patients with high risk for early death (22). Cohen *et al.* found five variables to be independently associated with early mortality: older age, dementia, hypoalbuminemia, diagnosis of peripheral vascular occlusive

disease, and negative response to the surprise question were used to develop an integrated 6-month prognostic tool that was validated for the prevalent hemodialysis population (23). Among octogenarians offered dialysis, predictors of death within 1 year included poor nutritional status, functional dependency, and late referral (24).

Finally, a growing amount of literature suggests that, for patients with a poor prognosis, RRT may not confer a significant survival benefit or prevent significant functional deterioration during the first year on dialysis (10–14). For patients over 75 years with characteristics suggesting a poor prognosis (Table 3), studies comparing dialysis with active medical management without dialysis do not uniformly show benefit to survival with dialysis (7,10–14), and the survival advantage, when present, may come with substantial burdens that negatively affect quality of life.

Likelihood of Renal Disease Progression before Death

Older patients lose renal function at slower rates than their younger counterparts, have a low incidence of progression to ESRD, and have shorter survival (6,24–29). Many older CKD patients die long before reaching dialysis because of significant cardiovascular mortality with higher stages of CKD (6,24–29). Older adults were 13 times more likely to die of any cause than progress to ESRD and six times more likely to die of cardiovascular disease than develop ESRD (27). The decline in renal function was slowest in CKD stage 4 patients over 75 years of age, and the higher the age, the lower the likelihood of living long enough to require dialysis (26). Irrespective of baseline renal function, patients over 85 years of age were more likely to die before progressing to the need for dialysis (6), and 30% of octogenarians followed over 4 years died of non-renal causes before RRT (28). More than one-third of patients over 80 years of age were found to have stable nonprogressive CKD, which was predicted by low levels of proteinuria, lack of hypertension, and low cardiovascular comorbidity (29). Thus, many older patients as well as those patients without deteriorating renal function or proteinuria may not progress to ESRD and the need for RRT.

Burdens of Dialysis and Risk to Quality of Life

For most patients considering RRT, the impact of dialysis on day to day life may be difficult to envision. The symptom burden in patients with ESRD is high, and along with increased comorbidity, it is linked to reduced quality

Table 3. Characteristics signifying a poor prognosis in older patients

<p>High comorbidity scores (<i>e.g.</i>, modified Charlson Comorbidity Index score of ≥ 8).</p> <p>Marked functional impairment (<i>e.g.</i>, Karnofsky Performance Status Scale Score < 40).</p> <p>Severe chronic malnutrition (<i>e.g.</i>, serum albumin level < 2.5 g/dl using the bromocresol green method).</p> <p>Nephrologist would not be surprised at their death.</p>

of life and depression (30,31), also common in ESRD (21). In addition to the occurrence of adverse physical symptoms while on dialysis, many patients experience multiple interdialytic symptoms, the aggregate of which can cause difficulty with activities of daily living (31). Furthermore, patients living distant to a dialysis unit must add the time and expense of traveling to and from dialysis, the long hours spent on dialysis, and a reduction in the time available for other activities (11–14).

The burdens of dialysis also include surgery for vascular or peritoneal access placement and their potential surgical complications. Primary maturation failure of the arteriovenous fistula (AVF) is reported to be as high as 60%, with the highest rates observed in older patients, females, nonwhites, and individuals with cardiovascular disease (32,33). An important prerequisite for achievement of a successful AVF is the presence of suitable vascular anatomy, the likelihood of which decreases with age and presence of many conditions common to patients with ESRD (32–35). Requiring all patients with advanced CKD, irrespective of age, to undergo AVF placement may be for naught in those individuals who are unlikely to live long enough to need their AVF for RRT. Faced with the possibility for little to no survival advantage with dialysis, older patients may be less accepting of such required clinical practices as well as the inter- and intradialytic symptoms that commonly accompany dialysis.

Clinically Meaningful Outcomes Are Relative

Dialysis can sustain life, but for patients suffering many of its indignities, dialysis may be viewed as merely a forestalling of death. Such a “clinically sustained existence,” as characterized by Kaufman *et al.* (8), fosters a sense of prolongation without progress—a place somewhere between getting neither better nor worse. This dilemma highlights the need for emphasis on clinically meaningful outcomes, the focus of which may be quality of life rather than quantity of survival.

Although the effects of initiating dialysis on patient status will vary between patients, current research suggests that functional status in older individuals is likely to decline rather than improve (16,36). The anticipation that chronic comorbid conditions will require hospitalization and the desire to die at home (or fear of dying while hospitalized) may be important considerations (9). Patients choosing dialysis over maximum conservative management survived three times as long but had higher hospitalization rates and were less likely to die at home (11); 1- and 5-year survival rates of veterans > 75 years of age on dialysis were 53% and 2.4%, respectively, although approximately 20% of time was spent hospitalized (37). Comorbidity did not independently predict mortality, and survival on dialysis was not

significantly different from survival of patients choosing not to pursue dialysis; however, significantly more patients choosing dialysis died while in the hospital (65%) than individuals who chose the nondialytic course (10). Disability and functional loss requiring caregiver or nursing home support were reported in more than 30% of octogenarians within 6 months of initiation of dialysis (36). For older patients suffering the loss of independence and other indignities of advancing age, meaningful components of the informed consent process may include symptom management, dying at home, and avoidance of hospitalization rather than duration of survival.

Informing Prospective Dialysis Patients about the Contingencies of Their Consent

The initiation of dialysis presumes the appropriate provision of informed consent (Table 4). Ideally, the process of informed consent begins as part of ACP long before a patient is faced with a decision about RRT. The importance of ACP is underscored by the high rates of withdrawal from dialysis (7), which is second only to cardiovascular disease as a cause of death and accounts for one-quarter of dialysis patient deaths (3).

The complexities of ACP for patients with kidney disease are of formidable magnitude (9) and confounded by preferences about dialysis that may change over time (38). Elderly patients evaluated before treatment for depression were rarely interested in dialysis as a life-sustaining therapy when depressed; after treatment, patients showed increased desire to pursue a variety of life-sustaining therapies subsequent to improvement in their depression (39). Factors influencing an older patient’s decision to start dialysis may be heavily weighted on functional status, the cognitive ability to appreciate quality of life, or even the perception (right or wrong) of the dying experience should they choose to forego dialysis. Low levels of cognitive function are highly prevalent in older patients with CKD (40); thus, many older patients may be less able to comprehend the magnitude of their disease, let alone the trappings associated with the day to day experiences of dialysis. Among elderly hemodialysis patients interviewed to determine whether informed consent for performing dialysis had been obtained, most of the patients lacked sufficient understanding and knowledge of their circumstances (41). Patients often do not understand the options (or the options presented may not include the option to forego dialysis), and many feel as if they have no choice (8). In situations of medical emergency, the presumed certainty of death is likely to trump any risk to benefit considerations that, under elective circumstances, might result in a different decision. Ironically, patients rarely include dialysis in the category of life support (9), although some view the act

Table 4. American Medical Association definition of informed consent

Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and a physician that results in the patient's authorization or agreement to undergo a specific medical intervention.

In the communications process, you, as the physician providing or performing the treatment and/or procedure (not a delegated representative), should disclose and discuss with your patient:

- The patient's diagnosis if known.
- The nature and purpose of a proposed treatment or procedure.
- The risks and benefits of a proposed treatment or procedure.
- Alternatives (regardless of their cost or the extent to which the treatment options are covered by health insurance).
- The risks and benefits of the alternative treatment or procedure.
- The risks and benefits of not receiving or undergoing a treatment or procedure.

In turn, your patient should have an opportunity to ask questions to elicit a better understanding of the treatment or procedure, and therefore, he or she can make an informed decision to proceed or refuse a particular course of medical intervention.

This communications process, or a variation thereof, is both an ethical obligation and a legal requirement spelled out in statutes and case law in all 50 states. (For more information about ethical obligations, see the American Medical Association's Code of Medical Ethics contained in the American Medical Association Policy Finder. Providing the patient relevant information has long been a physician's ethical obligation, but the legal concept of informed consent itself is recent.

The first case defining informed consent appeared in the late 1950s. Earlier consent cases were based in the tort of battery, under which liability is imposed for unpermitted touching. Although battery claims occasionally occur when treatment is provided without consent, most consent cases generally center around whether the consent was informed (*i.e.*, whether the patient was given sufficient information to make a decision regarding his or her body and healthcare). Because informed consent claims, unlike battery claims, are based in negligence, they generally are covered by liability insurance.

To protect yourself in litigation, in addition to carrying adequate liability insurance, it is important that the communications process itself be documented. Good documentation can serve as evidence in a court of law that the process, indeed, took place. A timely and thorough documentation in the patient's chart by the physician providing the treatment and/or performing the procedure can be a strong piece of evidence that the physician engaged the patient in an appropriate discussion. A well-designed, signed informed consent form may also be useful, but an overly broad or highly detailed form actually can work against you. Forms that serve mainly to satisfy all legal requirements (stating, for example, that all material risks have been explained) may not preclude a patient from asserting that the actual disclosure did not include risks that the patient, unfortunately, discovered after treatment. At the other extreme, listing all of the risks may not be wise either. A comprehensive listing will be difficult for the patient to understand, and any omission from the list will likely be presumed undisclosed. If you are using a form that contains a list, consider, with your attorney, inserting language indicating that the list is not exclusive (such as included but not limited to) before the list begins. Medicare-participating physicians must also be cognizant of Center for Medicare and Medicaid Services' requirements for informed consent.

Again, this general knowledge can be used when you ask for additional information and advice from qualified attorneys and/or other professional consultants. If you need a referral to a qualified attorney, please contact your state medical society.

of refusing a life-sustaining treatment (as opposed to foregoing a treatment that may or may not prolong life) as ethically or morally wrong. Most patients wish to receive detailed information about their condition to be prepared and plan ahead in case of death (9), and the vast majority desire information about their life expectancy and prognosis, whether positive or negative (42). A high percentage of patients, however, have not had these discussions with their nephrologists (43).

The increasing numbers of older patients starting dialysis, coupled with the persistently high withdrawal rates, might be thought to reflect a passive acceptance on the part of the patient, a lack of good judgment on the part of the physician, or both. Some patients with good cognitive function choose death over dialysis (44), citing satisfaction with the totality and finality of their life. An estimated 5–7% of patients with advanced CKD chose to forego dialysis or were not offered dialysis by their nephrologists (45). Significantly more patients with advanced CKD were not

referred for dialysis at all by primary care physicians (22%), who cited age as the primary reason for withholding treatment (60%) (45). By contrast, principle factors influencing the decision to not offer dialysis to octogenarians included late referral, social isolation, and poor functional status (24). The lack of data on frequency of withholding dialysis notwithstanding, patients making the informed choice to forego RRT and opt for medical management deserve a clear treatment plan with timely arrangements for active medical treatment during the end of life.

Informed Consent for the Dialysis Procedure Is Not Enough

Nephrologists' ability to predict outcomes has been significantly enhanced with the available predictive tools and evidence-based guidelines that can be used when counseling older patients about the burdens, risks, and benefits of dialysis (7) (Tables 1 and 2). Prognosis of the individual

patient is ultimately uncertain, however, and the ability to predetermine which patients will most likely benefit from dialysis remains a challenge and an area of needed research (17,46). This prognostic ambiguity should not limit but rather, encourage open discussions of the implications of either choice and as Swidler further advocates, communication processes should address and update goals of care as the effect of dialysis on a patient’s status becomes apparent: the “trajectory of decline progresses and end of life issues become more prominent” (47). When contemplating the propriety of dialysis, patients and nephrologists alike must anticipate and adapt to changes in patient status to assure an informed consent process that is individualized and dynamic. Unique aspects of ACP for patients with CKD include, in addition to the availability of replacement therapy for the failing organ, the opportunity to accept or refuse its implementation, a choice that is increasingly invoked (3). The finding that patients with nephrology care before starting dialysis had 50% lower risk of death because of withdrawal and cardiovascular disease in the first 120 days of dialysis (48) suggests a benefit of proactive discussion between patient and nephrologist. Specific issues to address include estimates of survival, impact of dialysis on daily life, projections of change in functional status, and alternatives of nondialytic management of progressive CKD

(Tables 5 and 6). When medical management is chosen in lieu of dialysis, ACP discussions that outline the activity of CKD treatment and the implementation of patients’ goals are recommended (7).

Discussion and Recommendations

Older patients (>75 years) with stage 4 or 5 CKD constitute a group for whom the dialogue of informed consent for initiation of dialysis has special implications. In patients advancing to dialysis, older age, functional status, and presence of comorbid conditions are important predictors of survival, and the likelihood of death before dialysis is formidable. Burdens inherent to dialysis affect patients uniquely and may constitute morbidity that is unacceptable to some individuals.

Estimates that care of the elderly will constitute at least 50% of patient encounters, coupled with the medical and socioeconomic complexities involved with elder care, highlight the need for knowledge of geriatric guidelines and training in this discipline (46). A systematic approach to ACP for patients nearing ESRD and the integration of shared decision making into medical care is espoused in the recent Renal Physicians Association guideline (7). Initiation of ACP early on in the continuum of CKD offers

Table 5. Specific issues to address in informed consent discussions with older CKD patients
<p>Dialysis may not confer a survival advantage over maximum medical management. Patients with their level of illness are more likely to die than live long enough to progress to ESRD. Life on dialysis entails significant burdens that may detract from their quality of life. It is likely that they may not experience any functional improvement with dialysis. They may undergo significant functional decline during the first year after dialysis initiation. Maximum medical management includes usual integrated CKD care. Palliative care is available irrespective of their decision to pursue or forego dialysis. Hospice is an appropriate consideration for patients with additional terminal illness.</p>

Table 6. Recommendations for providing informed consent to elderly patients contemplating dialysis
<p>Initiate advanced care planning early on in the continuum of CKD. Consider issues specific to age in informed consent discussions (Table 5). Determine and agree on the patient’s goals for both short- and long-term care. Integrate informed consent into ACP as part of the deliberation process when deciding whether to pursue RRT. Assure decision-making capacity and cognitive capacity for comprehension. Recognize the importance of life experience and tailor the discussion accordingly. Engage the patient’s family in the decision-making process. Distinguish informed consent for the option of dialysis from informed consent that is dedicated to the intradialytic symptoms associated with the dialysis procedure. Present estimate of renal and overall prognosis with and without dialysis. Present anticipated changes in functional status with and without dialysis. Explain traditional burdens of dialysis, including potential for both intra-and interdialytic distress. Explain risks of dialysis procedure, including those risks related to dialysis access. Explain current requirements of vascular access in the case of hemodialysis. Make plans for dealing with symptoms that could occur should renal failure progress faster than anticipated and/or faster than other comorbid conditions. Discuss desires for acute symptom management and goals to avoid heat of the moment decisions. For those patients choosing dialysis, discuss modality and dialysis access options, and explain the requirements and responsibilities associated with vascular access of hemodialysis or peritoneal catheter placement for peritoneal dialysis. Respect and assure the integrity of the informed consent process.</p>

patients and providers time for reflection and allows for a setting in which information is likely to be best received (49). Proactive discussion of patients' values and desires as they approach the end of life may preclude the need for hurried uninformed decisions, initiation of dialysis under emergent conditions, and passive acceptance of dialysis thereafter.

Sufficient evidence and ethical policy statements exist to support active medical management without dialysis, when "appropriate" or "reasonable," in certain patients with a poor prognosis (Table 3) and command a shift in focus from one of survival to one of maintaining quality of life. In such patients, the option to forego dialysis along with plans for CKD care management should be presented with objective enthusiasm on the part of the nephrologist. In patients for whom the prognosis is unclear, a time-limited trial of dialysis is an additional option. Issues to address and recommendations to consider in the informed consent process for older patients are presented in Tables 5 and 6.

The provision of informed consent for dialysis is more than a procedural document needed to legally initiate the dialysis treatment. Its importance as part of proactive ACP and the consequences of its engagement are magnified in older patients whose prognoses and life experiences will color decisions relevant to sustaining quality and quantity of life. Nephrologists are uniquely responsible for assuring the integrity of this process and its tailoring to the needs of the older patient. As their numbers expand, medical advancements continue, and new research sheds light on outcomes, the process by which we inform our elders and ultimately, accept their consent or refusal for dialysis will continue to command our respect and attention.

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