

Chapter 38: End of Life and Decision Making in Elderly Persons With Kidney Failure

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DEATH AND DYING IS INEVITABLE IN NEPHROLOGY PRACTICE

Mortality rates for end-stage kidney disease (ESKD) in the United States are well established through decades of national surveillance¹ and consistently average 15 to 20% per year for all patients who do not receive a kidney transplant. Thus, if one works in a chronic dialysis unit of 70 patients, one can expect to encounter at least one death per month. In the acute hospital setting, multiple studies^{2,3} have verified that patients who develop acute renal failure severe enough to require renal replacement therapy have a 50% chance of dying in the hospital irrespective of the type of renal replacement used and despite all of the technology presently available to support attendant multiorgan comorbidity. In both circumstances, age increases the odds of dying and frames how we must approach decision making with elderly patients.

Working with patients who have acute or chronic renal failure inevitably forces us to face patients who are dying. At the same time, a multitude of studies and quality-of-care initiatives put us on the spot and judge our practice decisions on the basis of outcomes that usually include mortality rates. It is no wonder that, even if we come to understand at some level that death is inevitable in our practice, there is great reluctance to talk about death and a persisting view that death is a “failure” of our medical skills or that talking about death will make it happen. This view is all too often reinforced by prevailing public sentiment and the media, and practitioners tend to focus on continuing intervention and cure rather than on the reality of progressive illness that often is at hand. In essence, we have not “naturalized” death as an inherent and inevitable event that we must learn to address if we are to deal with chronic illness effectively.

Case 1

Several months after the death of a very loving man who did home hemodialysis (HD) for many years with his wife's help, the dialysis social worker received an angry and critical letter from his teenage daughter, blaming herself but also asking why no one had prepared her family for her father's loss. She described how she and her sisters regretted not having the chance to say a loving goodbye to their father and how bereft their mother felt at his loss.

This particular case occurred early in our career with ESKD, and although we had an open relationship with the patient and his family, we failed to talk about death and dying because we felt that it was a taboo subject and because we thought that we might spare this patient and his family anguish by not talking about the prognosis for chronic dialysis or about end of life. By avoiding such discussion, we may have missed an important opportunity to help this family prepare and inadvertently contributed to the void left behind after his death.

As a nephrologist, I have learned that death is my companion, and the relationships that I develop with patients necessarily will include talking openly about end of life somewhere along the way. We began our own inquiry into the importance of these relationships shortly after Case 1 and during a particularly discouraging spate of deaths among our dialysis outpatients. Around the same time, the Patient Self-determination Act of 1990⁴ was enacted, mandating that hospitals offer patients the opportunity to execute advance directives at the time of admission and bringing this issue to the fore. In-

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stead of just second-guessing ourselves because of the recent deaths in our program, we decided to look at our experience with the death and dying process. We reviewed cases to see whether we had documented recognizing and discussing end of life before patients' deaths.⁵ What we found was that addressing death and dying, whether a formal advance directives document was executed or not, significantly affected the ultimate outcome for patients, families, and staff. Having such discussions favored a "good death" that was to some degree reconciled with a measure of closure and even relief. Other surveys suggest that patients on chronic dialysis expect medical staff to initiate these discussions,^{6,7} and the more experience we have dealing with death and dying, either our own personal experience or that with patients, the more prepared we are to undertake such discussions.⁸

One approach in the ESKD setting is to undertake more open discussion of these realities earlier in the course of encounters with patients. An opportune time occurs when the options for chronic kidney disease (CKD) are first presented, and now we often let folks know that, besides HD, peritoneal dialysis (PD), and transplantation, there is a "fourth option" that involves no dialysis but concentrates on comfort care if circumstances so warrant. Of course, most patients usually are not prepared to talk about the "fourth option" when first facing CKD, but it is an opportunity to establish that it is indeed an available option at the appropriate future time. In the acute setting, especially in the intensive care unit, it is important to keep the "no dialysis" option in mind, especially when other comorbidity accumulates and further intervention begins to look futile. In both settings, this type of discussion is more pertinent for the elderly in view of the prognosis that they face.

VOLUNTARY WITHDRAWAL FROM DIALYSIS: WHOSE CHOICE IS IT?:

Neu and Kjellstrand⁹ reported in a compelling article published >20 yr ago that 20% of deaths among chronic dialysis patients in Minnesota resulted from voluntary withdrawal from treatment. Soon thereafter, another report confirmed this experience among patients in Michigan,¹⁰ and in both studies, advancing age and the degree of comorbidity were important cofactors. For patients who withdraw from dialysis, death comes relatively quickly within 1 to 2 wk.^{1,9} More recent studies confirmed that a "uremic" death can often be managed in a home setting without undue suffering.^{11,12} However, it is common for patients and families to voice concerns that withdrawal from dialysis constitutes "giving up" or even "suicide," thus insisting on aggressive care that does not contribute to either quality of life or quality of death. Many patients, families, or even medical care staff members have not had personal experience with chronic illness or end of life in their own lives, and they are influenced by media sensationalism surrounding stories like those of Nancy Cruzan, Terri Schiavo, or Jack Kevorkian.

Case 2

A 17-yr-old high school athlete and scholar developed rapidly progressive glomerulonephritis with a multisystem illness that he survived but that required dialysis and then a kidney transplant. The transplant failed acutely with another multisystem illness, after which he went on peritoneal dialysis. Chronic pain and failure to thrive prompted University Hospital consultation. Now age 19, he switched to HD but continued to suffer pain and chronic depression, both of which defied adequate treatment. His family and medical staff avoided talking about prognosis and alternatives because he was "too young to give up," and pushed for parenteral nutrition and another transplant (from his stepfather).

The social worker arranged a family and staff meeting to discuss the options, during which his grandmother, who had recently lost her husband to a painful cancer death, "broke the ice" by reminding the family how her husband had withdrawn from futile cancer treatment and made a choice that our patient understood at the time it happened. His grandmother asked our patient if he had thought about that himself. Suddenly animated and with a clear sense of relief, he related how he thought about this often but worried about the impact on his family. His mother and stepfather were tearful but did not interrupt him and then shared that they did not know how he had tolerated all that had happened to him. Medical staff ventured that we could not predict the course of another transplant and all that might be entailed, and the patient, with his family's assent, declined and chose to withdraw from dialysis and spend his last days at home. A home visit several days later revealed an entire football team visiting and the patient looking more settled than we had ever seen him. His football jersey had been retired and framed, and that same evening, he was driven around the football field in his wheelchair during a high school football game dedicated to him. He died peacefully the next day.

Although this patient is young, his situation only emphasizes that it is not the age but the individual experience and personal circumstances that determine the appropriateness of withdrawal from life-sustaining treatments that we use for ESKD. Because this patient was young, we had our own agenda regarding the next set of decisions, an agenda focused on continuing toward the next life-prolonging modality. In the end, the patient along with the family member having the most life experience (his grandmother) were able to express how much he was suffering and ventured to open the door to discussing alternatives and to refusing more and more of what by now looked to be futile medical intervention. With the elderly, we are more apt to be open to the options, but age is not the sole criterion for this discussion.

DECISION MAKING: EXPLORING OPENLY AND WITHOUT AN AGENDA

Case 3

A 78-yr-old man develops renal cancer in his single remaining

kidney, 3 yr after the other kidney had been removed and 1 yr after angioplasty for acute myocardial infarction (MI) with congestive heart failure (CHF). Present quality of life is good, with a creatinine level of 1.8 mg/dl and some limited exertion tolerance. The tumor is located so that partial nephrectomy is not feasible. His urologist suggests nephrectomy and simply going on dialysis. The patient's sister had been a dialysis patient recently and had died miserably in the midst of severe complications. The patient came to our clinic seeking a second opinion.

Too often in our practice we focus only on curing the disease at hand, in this case removing the remaining kidney with cancer in it, without considering that we consign this man to ESKD when we undertake nephrectomy. We already have established that the prognosis for ESKD translates into a life expectancy of 5 to 6 yr on average, but for this man who is over 75, the mortality rate could be two to three times higher and translate into a life expectancy of only 2 to 3 yr.^{1,11} If we consider additional comorbidity factors that increase mortality risk further, including symptomatic heart disease, diabetes mellitus as the cause of CKD, significant peripheral vascular disease, and poor functional status as indicated by the Karnovsky scale,^{1,11} the outlook for doing nephrectomy gives one pause. These statistics do not even address potential impaired quality of life, the intrusiveness, and the daily "hassle" that often are part of chronic dialysis and that loom ominously for all patients but especially for the elderly. Ironically, the overall prognosis¹¹ for renal cancer *in situ* is at least as good as that for ESKD¹¹; thus, even if we cannot predict exactly how the clinical course or potential complications will unfold, we cannot simply assume *a priori* that removing the cancer (and the remaining kidney) is the optimal treatment. In the final analysis, we must seriously look at aspects of our decision that we might not have initially considered.

Looking at outcome data in this way, there is always the danger that we begin to take on an impersonal approach, impart the data, and leave the decision to the patient. At the same time, it is difficult not to have our own bias and agenda in going over situations like this one. Listening to the patient's viewpoint and finding the right balance between what we know and what we don't know, or what we view as the best medical decision and what actually fits the patient's goals, is an art that is only learned through experience and that is poignantly illustrated by this case. Often there is no one right answer, and sharing the exploration establishes a trusting relationship in which we can empathize with the patient's dilemma and share in what may well be an ongoing process aimed at choosing the optimal solution for the individual.

THE PALLIATIVE CARE MODEL: ACUTE VERSUS CHRONIC ILLNESS

The principles of "palliative care" articulate our understanding of how chronic illness is distinct from acute illness. Clearly we

can "cure" or restore health after some "acute" illness such as pneumonia, fracture, or even acute myocardial infarction. However, we cannot cure most "chronic" illnesses and can only contain them. ESKD is an excellent example of such a condition. In any illness, acute or chronic, palliative care is that care focused on promoting quality of life and not simply on prolonging longevity.^{13,14} If treatment can prolong life while also promoting quality and comfort, then so much the better.

Figure 1 shows the interrelation between acute and palliative care during the course of chronic illness, emphasizing the increasing importance of controlling symptoms instead of curing disease as chronic illness progresses. This scheme does not imply that we ignore medical complications that can be corrected but rather that, for each and every therapeutic decision, we weigh the impact of our intervention on quality of life and symptom control *versus* the quantity of life and its prolongation at all costs. In a sense, it is valuable to view dialysis itself as a "palliative" intervention and to consider its contribution to the quality rather than to the quantity of life.

These distinctions between quality and quantity of life are not always so clear cut, and the process of making choices often takes time, requires several discussions, and creates tension as we walk a tightrope between continuing full-court pressure and letting go.

Case 4

The Palliative Care team at our hospital was called to see a 43-yr-old man with congenital heart disease and previous stroke, who presented with biventricular failure, hypotension, and renal failure, all progressing despite infusions of cardiac supportive agents. His sister was his major care provider and was the decision maker both for him and for his elderly mother. He had been functional until recent months despite his chronic illness, but became severely confined and continuously breathless except when kneeling at his bedside. We discussed comfort care at home with Hospice support. We also considered the role of dialysis to improve his heart failure, noting that HD would pose hemodynamic difficulties and that PD was feasible but would require substantial home-based care. The patient and his sister still clung to prolonging life unless and until they could see no way out, and they chose to defer both Hospice and dialysis in favor of one more trial of cardiac supportive agents infused at home.

He returned to the hospital within a few days with more dis-

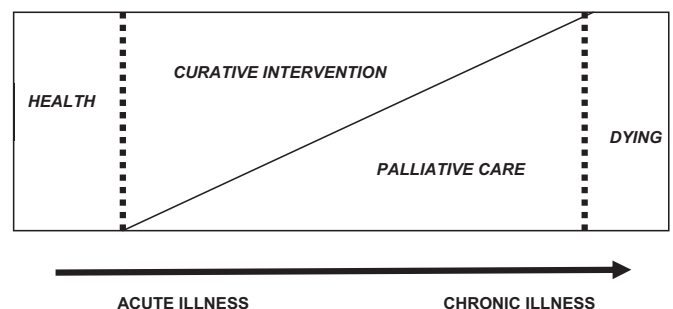


Figure 1. The trajectory of care during chronic illness.

tress and worse renal failure. Together we agreed on a time-limited trial of PD. PD was extremely helpful and improved his CHF to the point he could walk, sleep in bed at night, and function at home. His sister managed to balance her work and the caring for him and for mom during the ensuing 14 mo. Eventually, he developed refractory arrhythmias that required intensive care unit treatment and culminated in withdrawal of support by his sister with their mother's understanding and support.

Situations like his one demand shared decision making with active listening and flexibility rather than an agenda and assumptions about the best medical course to take. Here a "time-limited trial" of dialysis provided substantial symptom relief and improved quality of life for an extended period. This reprieve also resulted in solid grounding from which the eventual decision to voluntarily withdraw dialysis care became a reconciled and acceptable choice.

SHARED DECISION MAKING IN ESKD: A PROCESS AND NOT AN EVENT

There is no substitute for undertaking direct discussion with patients and families about quality of life, prognosis, and the possibility of death and dying. The recent document "Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis: Clinical Practice Guideline"¹¹ is an excellent resource that includes a series of recommendations for such discussions along with appended medical, psychologic, and epidemiologic data relevant to both the acute and chronic renal failure settings. Such discussions need not wait for a crisis situation, and there are many opportunities to explore patients' fears and questions or to articulate their goals of care. Some starting points for discussion might include talking about CKD planning or advance directives, any juncture at which there might be potentially serious treatment complications, or even simply obtaining informed consent for a procedure.

When critical illness does develop, the discussion takes a different turn and often focuses pointedly on bad news, requiring a thoughtful and deliberate approach. There are a number of very helpful resources that offer suggestions for organizing family meetings¹⁵ and for actually delivering "bad news."¹⁶ Effective discussions require some planning that includes inviting the necessary participants, choosing an appropriate quiet setting, establishing what participants have already heard, exploring what new information participants are ready to hear, giving an optimal amount of information that can be absorbed, checking out what everyone has heard, and planning for any subsequent meetings or actions that seem necessary. Listening well and being prepared to follow-up on unexpected developments may be pivotal to the success of such discussions. A family meeting has value even when the situation seems unresolved and chaotic because any subsequent discussions will have been affected, and will start one or two steps

ahead. We can, at a minimum, learn what participants already know, discuss the goals of treatment, allow for input by family members who need to express, make pertinent suggestions, and assure that all participants hear the same discussion.

Case 5

A 67-yr-old man with previous peritoneal dialysis and then several years with a chronically failing transplant was now back on HD. Progressive cardiac and peripheral vascular disease limited his function and well being, making him increasingly dependent on his wife, who often asked the questions and made the decisions. As his condition deteriorated, he asked to withdraw from dialysis. At a family meeting, it was clear that his wife and daughter were angry, blamed him for not trying harder, were unwilling to support withdrawal of ongoing medical care, and refused to have him at home if chose to withdraw from dialysis. After the meeting when his family was gone, we suggested to him that his family seemed uncomfortable making this decision for him and that when he died he would leave much anguish and anger. We suggested that he discuss his feelings more openly with his family, specifically that he was suffering and in pain, that he still loved them, and that they were in no way to blame for his difficulties.

Two days later his wife brought him for scheduled HD, asking if we would admit him for terminal care. His scheduled dialysis was deferred, and a family meeting was quickly arranged. His wife related that now she understood his situation more clearly but that she could not physically care for him at home. She asked if we could admit him so that she could stay with him at the hospital. Other family members agreed. The patient was admitted and died peacefully within several hours with his wife at his bedside.

Learning to navigate the journey through ESKD and end of life does not come naturally. The skills are acquired by actually making the journey with patients, by developing authentic relationships that do not hide our humanness, and by allowing dying patients to contribute to us. In addressing goals of care and discussing medical choices, we learn to accept our own limitations as medical practitioners and give some autonomy and responsibility back to the patients. The challenge may seem daunting with end points that are different than those we originally conceived, but the process can be the very gratifying for us and contribute immeasurably to reconciliation for patients and families.

TAKE HOME POINTS

- Life span is shortened for patients with ESKD and with AKI as well, and death is an inevitable clinical event in nephrology practice
- Learning to talk about death and dying is an outgrowth of long-term relationships with patients and families that serve all parties well in this process; these issues are obviously nearer and more pressing in elderly persons but are equally germane to dialysis patients of all ages
- Talking about advance directives helps to focus our discussions on chronic illness and on patients' fears that ultimately favor patient, survivor, and staff reconciliation when death does occur

- Patients are often prepared to talk about death and dying, and as many as 20% of patients will eventually withdraw voluntarily from dialysis when quality of life deteriorates; addressing these issues directly and viewing treatment decisions from a “palliative care” perspective that focuses on quality rather than quantity of life, sometimes to withdraw from treatment, but sometimes to continue treatment
- Shared decision making is pivotal and includes sharing available prognostic information, answering questions sensitively and directly, making sure all involved parties participate and are heard, and continuing the relationship and discussion throughout the course of illness
- Family meetings that include pertinent medical staff and facility at delivering “bad news” sensitively are essential tools of the trade that are learned only with experience

DISCLOSURES

None.

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REVIEW QUESTIONS: END OF LIFE AND DECISION MAKING IN ELDERLY PERSONS WITH KIDNEY FAILURE

1. Mortality in end-stage kidney disease:
 - a. Is affected by age and the presence of heart disease and diabetes
 - b. Averages as much as 20% per year or more
 - c. Is >50% per year in persons >80 yr old
 - d. all of the above
2. The odds of in-hospital death for persons suffering acute kidney failure:
 - a. Are 50% overall
 - b. Average >50% if renal replacement therapy is required
 - c. Depend on the type of renal replacement therapy chosen
 - d. None of the above
3. Advance directives:
 - a. Have a major impact on outcome
 - b. Prompt discussion between patients and care givers about medical choices
 - c. Have no particular impact because they are often ignored
 - d. Have specific legal standing in most jurisdictions
4. Voluntary withdrawal from dialysis:
 - a. Occurs rarely in the usual clinical setting
 - b. Results in unacceptable acute symptoms and uncomfortable death
 - c. Is not legally acceptable in most states
 - d. Is more common with increasing age and comorbidity
5. Family meetings in the clinical setting necessarily involve all of the following except:
 - a. Inviting all vested parties in family and medical care team(s)
 - b. Identifying a quiet setting that minimizes interruptions
 - c. Finishing with a plan that obviates the need for further meetings
 - d. Verifying what participants already know and still need to know