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The value of 'life at any cost': Talk about stopping kidney dialysis

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Abstract

With the trend toward an older, sicker dialysis population in the USA, discussions of ethical issues surrounding dialysis have shifted from concerns about access to and availability of the therapy, to growing unease about non-initiation and treatment discontinuation. Recent studies report treatment withdrawal as the leading cause of death among elderly dialysis patients. Yet, the actual activities that move patients toward stopping treatment often remain obscure, even to clinicians and patients themselves. This paper explores that paradox, drawing on anthropological research among patients over age 70, their families, and clinicians in two California renal dialysis units. It concludes that many older patients sacrifice a sense of choice about dialysis in the present to maintain "choice" as both value and possibility for the future. Yet, patients desire more information and communication, provided earlier in their illness, about prognosis, how long they can expect to be on dialysis, and what the impact of the treatment will be on their daily lives. That, with time, there is a transition to be made from dialysis as "treatment" to end of life care could be better explained and managed to alleviate patients' confusion and unneeded isolation.

Keywords

USA; end of life; decision-making; kidney dialysis; old age; medical technology

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> What we do in the unit, it's a miracle. We keep people alive, many of them pretty well. But it's abrupt—we try to do in three hours what the kidneys do in forty-eight—and some of the old people don't tolerate it well. Right now, you do everything because the technology is there. I view it as being driven by a culture of 'life at any cost.' It used to be that families wanted to stop and doctors wanted to go on… Now, it's the reverse, and courts have basically decided families have the right to request therapy even if it's futile. Meanwhile, the populace has gotten less frightened, less bewildered by the technology of medicine. It doesn't trouble them as much as it once did. So Grandma has six feeding tubes and seventeen IVs and a respirator and a whatever—bring it on. (Nephrologist)

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Introduction

Among the array of medical advances to extend and enhance late life, the dialysis of elderly individuals poses distinct dilemmas of identity and meaning. While patients may live longer on dialysis, that “extra” time is achieved only through a corresponding investment of time and effort, as patients give several hours, three days a week to a treatment many find exhausting. The result is a circumstance partly empowering and liberating (from the limits of the diseased body), and partly anxiety-producing (because life depends on continual reconnection to the dialysis machine). In a situation where the burdens of treatment and remaining alive can for some rival those of illness itself, many older patients are forced to confront the value for them of persisting on dialysis.

This paper examines the value of the extended old age made possible by dialysis. That value is partially revealed in patients’ and clinicians’ demonstrated commitment to therapy and the perpetuation of life. It is also explicitly described in their ruminations about treatment discontinuation—about those circumstances wherein it might be determined living no longer holds the worth that it once did, that it still should, or that life itself no longer justifies support. Previously, we noted that many older patients describe feeling suspended between life and death on dialysis (Russ, Shim & & Kaufman, 2005). Most patients, though, also express the desire to live, and continue dialysis despite their only dubious sense of having “chosen” the treatment in the first place. Here, we focus on older patients’ and clinicians’ remarks about *not* continuing treatment, and the indeterminacies of value and patient choice those comments raise.

Methods

We draw on accounts of patients age 70 and over and their clinicians in two California renal dialysis units where, between 2003 and 2005, the first author conducted participant-observation and formally interviewed twenty-one clinicians and forty-three patients between ages 70 and 93. One is an inner-city unit, affiliated with a large teaching hospital; the other is a private unit, located in a well-to-do suburb. At both, patients over 70 comprise over half the census. Many live with multiple ailments in addition to end stage renal disease (ESRD), including diabetes and hypertension, cardiovascular disease, and metastatic cancer. The issues explored below were equally present at both units.

Research involved attendance at pre-dialysis and physician-patient meetings and observation of routine hemodialysis in the outpatient units. Initial interviews with clinicians (n=21; 4 physicians, 5 nurses, 5 social workers, 2 dieticians, 2 technicians, 3 administrators) lasted on average one hour, with frequent follow-up in the clinics. Interviews with patients (n=43; 27 women and 16 men; 24 White, 13 African-American, 5 Asian, 1 Latino) took place as patients dialyzed, and ranged from 1–2 hours (sometimes over multiple sessions). Interviews were conducted also with seven family members (3 wives; 1 husband; 2 daughters; 1 son). Research was approved by the Committee on Human Research at The University of California, San Francisco.

Interviews and observations among patients and families focused on: factors influencing decisions to initiate dialysis; experiences of treatment over time; perspectives on the long-term goals of treatment; role of the family in therapy and decision-making; and hypothetical conditions under which patients might cease therapy. Decisions and actions to stop treatment, which generally occur in the hospital and/or when death is imminent, were not observed. Interviews with clinicians explored circumstances surrounding decisions to initiate and discontinue treatment, as well as instances of patient withdrawal. Data were analyzed using principles of grounded theory (Strauss & Corbin, 1998), in which interview transcripts were open-coded to identify and group substantive themes. Codes of specific interest for this paper included the ways in which patients and clinicians discussed stopping therapy and/or made more or less proactive steps to do so. In this paper, we emphasize clinicians' perspectives.

The ways patients and care providers both do and do not talk about treatment discontinuation, and the near invisibility surrounding the actual withdrawal process, reveal much about the ethos of dialysis today and the nature of medical decision-making around this treatment modality. Together, their comments also evince the difficulties and responsibilities associated with choosing or authorizing death, and what it means to say “no” to this one weapon in a growing arsenal of medical procedures and therapies for prolonging late life (Kaufman, Shim, & Russ, 2004).

The emergence of geriatric dialysis

Renal dialysis emerged in the 1940s and 1950s as a short-term procedure for persons with acute, life-threatening kidney failure. In 1960, with the advent of “maintenance” hemodialysis for the continuous treatment of individuals with irreversible loss of kidney function, practitioners entered an ethically ambiguous realm in which life could be sustained indefinitely without curing underlying disease. Sociologists Renee Fox and Judith Swazey (1974, p217) early on queried whether long-term support on dialysis would constitute a blessing or “merely a labored and painful hanging onto life.” Their question has acquired urgency in the decades following 1972 legislation extending Medicare benefits to all citizens with ESRD (Rettig, 2001). Whereas physician advocates of that legislation predicted the U.S. dialysis population would “stabilize somewhere around 20,000 patients” (Levy, 1974:4), it presently exceeds 300,000.

Unforeseen by early practitioners was the shift toward an increasingly aged, disabled dialysis population, many of whom would once have been ineligible for the treatment. In 2002, nearly half the U.S. dialysis population was over age 65; patients over 75 now comprise the fastest growing group of recipients (Oreopoulos & Dimkovic, 2003). The “gerontologization” of dialysis has come at considerable cost in Medicare dollars, prompting some to question its suitability for older patients whose lives, by objective criteria, may be only marginally lengthened. For patients over age 80, median survival time on dialysis is less than two years (Tattersall, 2005). In Europe (including the U.K., which through the 1970s and 80s applied the most stringent age-specific criteria for treatment), the numbers are comparable (Rothenberg, 1992; Stanton, 1999). Over half of European patients undergoing dialysis in 2003 were over age 65 (Sims, Cassidy, & Masud, 2003). There is wide variation across countries in the rates of ESRD patients initiating hemodialysis: 310 patients per million population in the U.S.; 77 per million in the UK; 148 per million in Germany; and 104 per million in Italy (Lambie, Rayner, Bragg-Gresham, Pisoni, Andreucci, Canaud, et al., 2006).

The predicament of ever more older individuals nearing the ends of their lives on dialysis has, with few exceptions, not been addressed in the medical literature (Cohen, Germain, & Poppel, 2003). Nor has it significantly altered the clinical ethos of dialysis units themselves, which simply emphasizes that dialysis allows and extends life. Yet, mortality rates for patients on dialysis – especially older ones – are high. Nearly 25% of the U.S. dialysis population dies each year, with the elderly, demented, and severely ill overrepresented among those deaths (Cohen & Germain, 2005). While in that sense death is normative among this patient group, the ever-present possibility of death in the units is not explicitly elaborated. Instead, patients and providers remain largely “united in denying the dying that is a regular part of ESRD and dialysis” (Cohen, McCue, Germain, & Woods, 1997:31).

But underneath this clinical emphasis on life loom questions about the appropriateness and duration of therapy and about “quality of life,” particularly for elderly patients. The relationship between age and quality of life on dialysis is not simple. Early accounts of the treatment posited that older patients adjusted more readily to dialysis and its associated restrictions—for example, the rigid time schedule and loss of freedom involved—than did younger patients (Fox & Swazey 1974, p277–9). Dialysis was seen as simply an extension of what was already happening to older patients—i.e., that they were becoming weaker, less active, more tired—as opposed to the sea change in identity and day-to-day life it involved for younger patients. Recent studies are more equivocal (Kutner & Jassal, 2002, p108). Some have found older dialysis patients to be at increased risk for loneliness, depression, and impaired physical functioning. At the same time, researchers have noted a positive correlation between advanced age and life satisfaction on dialysis, particularly among African-American patients. Patients themselves question why they work so hard to stay alive. For those who are relatively healthy, active or socially connected, the answer may be close at hand. For others who are profoundly sick and made inactive or weak by the treatment, who experience ongoing problems with their dialysis access or their transportation to and from treatment, or who are depressed or lonely, the burdens of therapy may compound those of disease.

Medical studies indicate anywhere from 22–28% of U.S. hemodialysis patients who die each year—most of those elderly patients—cease therapy prior to death, making treatment discontinuation the leading cause of death among patients over 70 (and second leading cause for patients overall) (Luke & Beck, 1999). Munshi and colleagues (2001) report that withdrawal from treatment precedes death for 38% of U.S. dialysis patients over age 75. Discontinuation from dialysis is also reported as the first or second most common cause of death among patients in the U.K., Australia, and France, though it appears to be less common elsewhere in Europe and Japan (Sehgal, 1996; White & Fitzpatrick, 2006); variation could stem from disparate reporting methods for dialysis withdrawal in different countries and centers (Birmele, Francois, Pengloan, Francais, Testou, Brillet, et al., 2004). For those who stop, death usually comes within a matter of weeks or days.

Despite the prevalence of dialysis withdrawal, there have been few qualitative studies of the topic. Exceptions are the Baystate Dialysis Discontinuation Study (Cohen, Germain, Poppel, Woods, Pekow, & Kjellstrand, 2000), and a recent study of dialysis abatement in Melbourne, Australia (Ashby, op't Hoog, Kellehear, Kerr, Brooks, Nicholls, & Forrest, 2005).

In contrast to published reports on the prevalence of discontinuation, clinicians we spoke to insisted that voluntary withdrawal from dialysis is “extremely rare,” that it virtually “never happens.” Likewise, patients and families—even those who have “chosen” to stop treatment—often do not report or acknowledge they have made that choice (Van Biesen, Lameire, Veys, & Vanderhaegen, 2004). How could this be?

In the divide between what is and what is spoken, dialysis units are contradictory spaces for elderly patients: committed to life but in which death is an unspoken constant; obligated to patient choice but wherein choices are felt to be absent and seem not to be experienced. The act of proactively allowing death remains invisible in these settings partly because both the potential of treatment withdrawal to allow death and death's gradual encroachment are themselves so poorly recognized. Questions about value and about the social and existential ramifications of living indefinitely on dialysis also remain backgrounded in this clinical milieu where clinicians and patients are immersed in their immediate, instrumental efforts to assure that life continues. Comments about treatment cessation, when those emerge, tend to be brief and, when uttered by patients, less than fully formed. The relationships between patients' and clinicians' discussions, decisions, and actions to stop treatment are, furthermore, not always clear. Yet, altogether, their statements reveal a preliminary attempt to reflect on a new form of late life being achieved in these units.

Findings

For many older patients on chronic dialysis, life support does not reduce the apprehension of death so much as enliven and expand it as an experiential domain. While older patients generally *accept* dialysis treatment, given the alternative of death, they do not *choose* it. For many, their passive acceptance later generates profound questions about the meaning and worth of the therapy—and more importantly, about the worth of their lives on the therapy. That is, bubbling under a veneer of straightforward participation in the treatment are doubt, ambivalence about what is gained and lost in the treatment process, and confusion about the goals of therapy. Questions persist through subsequent weeks, months or years of treatment; for example: Do I really need this? Can I ever get off? When will this end? Why am I here?

The following themes emerged as central to patients and clinicians when they considered the topic of discontinuation: what is said (and heard) about stopping dialysis; patient choice and quality of life; questioning life on life support; unclear family role; passive non-compliance; events leading to discontinuation; and choosing (death) later.

What is said and heard about stopping dialysis

Clinicians emphasized that patients choose to voluntarily terminate dialysis “very rarely.” Nor, most insisted, do older patients typically initiate conversations about discontinuing treatment or address the subject directly in conversations with medical staff. In our discussions with patients, we, too, found that people in the routine course of dialysis do not talk about or want to consider stopping therapy. Only five patients we interviewed specifically addressed the topic of treatment discontinuation without prompting. For most, it is simply too overwhelming to engage the big questions of meaning raised by this technology and the potential decision-making about the timing of death it provokes. “I’ll cross that bridge when I come to it,” was a characteristic response to our queries regarding the circumstances that might lead one to consider not continuing treatment.

Yet, we also found that patients do obliquely and regularly address the topic of stopping treatment, though not in ways recognized by clinicians as clear statements regarding treatment choices. The subject comes up in patients’ comments they have “had enough,” are “too old,” too “tired,” and they “just don’t want to do this anymore.”

Patients’ appeals that they are weary, “sick of coming here,” or, not uncommonly, that they believe they are made sicker by the treatment, are difficult for clinicians to assess. Staff have trouble distinguishing “genuine” entreaties from “reasonable” complaints made by patients in the clutches of a difficult disease and demanding therapy. Talk about discontinuation, in other words, may not constitute or may not be understood as talk about actually discontinuing. Many clinicians interpret statements about not wanting to continue as evidence of potential depression. Cohen & Germain (2005) review the medical literature concerning the relationship between depression and death-accelerating decisions among dialysis patients. In their Baystate study, they did not find depression to be significantly elevated among the subgroup of patients who discontinued dialysis. However, they concur with Ganzini, Lee, Heintz, Bloom, & Fenn (1994) that patients with severe depression should be encouraged to postpone decisions about end of life care options pending antidepressant treatment. A technician explained:

> There’s a patient right now, he’s 83. Every time he comes in, he’ll say, “I don’t want to go on with this; I don’t want to continue; this is too much for me.” Maybe we need to change his code status. But first, let’s see if he belongs on antidepressants. If he still brings it up, then think about changing his status, then think about discontinuation.

Clinicians grapple with what constitutes a normal level of “situational” depression and what is “clinical.” “Her case is situational,” mused a social worker about a patient who had “brought up discontinuation here and there." "She's miserable and feels dialysis is the culprit. But she doesn't want to withdraw from dialysis; she wants to withdraw from the symptoms. It's confusing because the signs of depression—not eating, failure to thrive, not sleeping, sleeping too much, crying—get confused with the symptoms of dialysis." Thus, patients are seen to speak situationally and symptomatically, their comments construed within the imperative to treat and the assumption that the desire to pursue treatment, and life, is "natural," even if the technology is not.

Practitioners also are uncertain as to what degree they should entertain patients' statements about "not wanting to go on" that might be uttered on a bad day, or just after a patient's spouse has died, or during the early stages of a therapy seen to involve a trajectory of patient resentment followed by adjustment. There can be a shift in how they hear patients' pleas over time:

> Most people want to live. It's not until they initiate treatment and realize all the symptoms associated with it, and how their entire life is going to change that it hits them. This is where you get stuck ethically. Maybe they only started dialysis a few months ago and still don't see any major improvement. Maybe other things are going on: their partner has died, and all they can think about is wanting to be with them. They know if they stop dialysis, they'll die. So they'll say, "I don't want to do this anymore." I sit down with them and sort it out. "Are you aware of what you're saying? Is it that you don't want to come to dialysis, or you don't want to live anymore? Or do you want a shorter treatment, or to come only twice a week?" Then, there are patients, you can see they're genuinely ready. They've been on dialysis ten years. They've had both legs chopped off. They've had it. Staff are generally supportive of those decisions. (Dialysis Nurse)

Patient choice and quality of life

Staff do not always agree about what patients should be "allowed to choose," or how actively they should advocate for patients who express the desire to stop treatment. "Some nurses bring it up," commented a nurse; "I don't." She expressed discomfort with nurses in her unit who are "sticklers about patient choice," who "harp" on the subject. To her, even the formal recitation of patients' right to discontinue therapy, made when long-term care plans are annually reassessed, seems excessive: "It doesn't make any sense because *of course* it's an option. I don't think you have to be told this." She questioned whether it is not best for clinicians simply to encourage patients to do their best on the therapy.

At any rate, another nurse explained, it defies explanation who finds the treatment bearable and who does not; that is the "mystery of quality of life on dialysis." Sometimes, the patients she believes have it easiest in terms of financial, family, or intellectual resources are precisely those who complain most bitterly about treatment. She therefore takes patients' statements about wanting to stop "with a grain of salt," and would be loath to bring it up herself. She offered as an example a patient she views as having "zero quality of life" on dialysis, yet who has never expressed the desire to stop. Her language reveals the intimacy that can develop between clinicians and patients in a chronic treatment setting, rendering more difficult staff's ability to hear and disentangle patients' desires from their own:

> There's one patient—nothing interests her anymore. She has no energy. She had a dog, but he died a week ago. She loved that dog. I'd tell her, "take him out for a walk, just do <u>something</u> to make your quality of life better. Go outside! Look at the sun!" But she never did. She doesn't believe she has any quality of life. She says that. Yet she's not even thinking of stopping dialysis. Never once has she said, I think it's time to stop. So I don't say that either. Ever. You want your caregiver to want you to come, to get on the phone and say 'get in here.

A patient who recalled being “nagged” by nurses to come into dialysis agreed; she registered their entreaties as a “sign of caring.” Another nurse added that “bringing up discontinuation is dangerous,” because patients can mistake clinicians’ comments about stopping treatment as threatening revocation of their care. A 73-year-old woman in the final stages of lung cancer illustrated her point. Several times, this patient cried that she was exhausted, that she could barely climb into the taxi to get to and from treatment. Yet, when her oncologist urged her to consider whether dialysis was yielding any longer the benefits and “quality of life” she wanted, she interpreted his query as evidence her clinicians were no longer committed to her well-being:

> My doctor wants me to commit suicide! I can’t give life, only God can give life. Black people don’t commit suicide! Why couldn’t they give me [a little] longer? I’m not an animal, I’m a human. Would the doctor recommend this to his wife?, his children? Then he asked if I were to have a heart attack [on dialysis], would I want them to revive me? What’s this about a heart attack?! I’m very hurt.

Questioning life on life support

Other patients wished clinicians would more fully engage their comments or queries about wanting to stop treatment. For them, such comments were, at times, serious and, at other times, an effort simply to discern the goals of therapy or likelihood of ever living without it—issues about which patients remain confused. “I want to get off dialysis,” stated an 83-year-old woman who had started dialysis two months before. “At least, I want to shorten it. I’m probably in denial thinking either of those will happen. But they don’t tell you how long to expect! Do *you* know how long [one] can go on like this?”

Patients often do not understand, in beginning treatment, what they have assented to, the commitment it will entail, or that it will be for the rest of their lives. Indeed, many do not gather until well into therapy that they are, as the son of one patient put it, “on full life support” and that, without dialysis, they will die. “When they begin to see themselves as *completely* dependent on systems to keep them alive, that’s when you start hearing them talk about death and dying and they just don’t see themselves ‘going on this way’,” noted a social worker; “they don’t feel their life is their own anymore.” According to the son, the moment his mother realized she could not live without dialysis was the moment, for her, life began to wane in value:

> For us, it started with an emergency situation in the hospital. It’s presented as short term treatment. It doesn’t click, wait a minute, this is full-on life support. And it was probably three years before she even started saying or admitting it was life support. To her, it was just treatment. That was a big shift, when she started saying that. That’s when she started talking about not doing it anymore.

Because patients often do not fully recognize that without dialysis they will die, they likewise do not always equate ending dialysis with hastening or allowing death. “After they’re on dialysis awhile, they’ll say, ‘So how long am I gonna be on this?” a nurse stated. “I’ll say, ‘Forever.’ ‘Has anyone stopped?,’ they’ll ask, ‘What happens if you stop?’ When I told one patient, ‘You’d die,’ his eyes got so big. He was shocked he needed this to stay alive.” And while some patients “are at an age where quality of life is such that they don’t think they have quality of life,” added another nurse, deciding life no longer holds value is different than ending it. She noted the shift in end of life conversations as patients continue, and deteriorate, on the therapy. Whereas those conversations can have a rote, procedural aspect early on, they become more pressing later:

> I have end of life discussions when I first meet patients, to explain advance directives. But that’s not practical enough. You do it because you need to legally. It’s not like the conversation, “You don’t look so good. What do we want here? Do we want to

> keep going?" Conversations become more meaningful when we see a failure to thrive; when patients are telling me they don't want to live anymore 'cause they feel so bad; when they're not adjusting—and they simply want no pain. But they don't understand achieving that will be the end of their life.
>
> There's a patient who keeps telling me all she wants to do is go home, lie in bed, and not do dialysis; she wants peace. But when you push her, "What does that mean? Do you want to end your life?," she says "No," she won't go to that point. So it's a hard discussion to have with patients—because you have to put it in such practical, harsh terms. And you avoid that. Yet, it comes up, when someone is agitated on the machine or isn't doing what the medical team recommends: "What is your purpose in being here? Do you want to continue? What would it mean if you didn't? You would die is what it means." Most patients, therefore, are evasive in their answers, they say they "have to think about it," they push it aside. They're not willing to admit they want to give up.

Unclear family role

The role of family in the discontinuation process is unclear. Some clinicians indicated that patients with involved families are *more* apt to stop treatment because proxies are available to make decisions should patients become acutely ill or incapacitated in the hospital. Others suggested that patients with family are *less* likely to stop because those patients want to remain with family and protect them from grief. A social worker described how, in one case, family —in its presence or its absence—would likely play a prohibitive role:

> We have a patient in her 80s. She's extremely confused. She regularly talks about death and dying and attending her own funeral. She cannot stand the rehab hospital where she's living. Basically, she's not thriving—she's experienced rapid weight loss; she's unhappy; she hallucinates. In her situation, if there was no family for us to consult, she'd probably continue on dialysis till she passed away. If there was a family member, then the conversation would probably be had with that person. My experience, though, is that family members don't like to make these decisions. So if she's not able to make the decision [to stop] herself, it probably won't be made by them.

Families do not perceive a clear distinction between allowing death and choosing it, making any such decision fraught with guilt. They prefer, a nurse explained, for death to "happen naturally." A unit director expressed frustration that families of extremely ill patients may agree to a DNR (Do Not Resuscitate) order or to forgo life-saving options in the hospital and, thereby, *acknowledge impending death*, but not be similarly willing to consider the option of discontinuing dialysis treatment to *allow imminent death*:

> Families don't want to withdraw dialysis. We're in a situation now where a patient is coming in literally comatose, very poor blood pressure with dialysis. The family doesn't want to discontinue and the physician doesn't want to override their wishes. So I'm being asked to dialyze a patient that's not appropriate. The family has agreed, if she's acutely ill, they won't take her to hospital. So if she dies at home, fine. But they won't take the extra step to say, I'm not gonna send her to dialysis anymore. So I've got to put down ground rules. If the blood pressure is not a certain level, I cannot dialyze her. She needs in-house, one-on-one dialysis. So if you want her dialyzed, you need to get her hospitalized.

"The family won't hear of it," noted a social worker, "so patients don't feel they're allowed to stop treatment." Instead, she implied, families prefer withdrawal from treatment to remain an inarticulate process, driven by "objective" medical criteria rather than personal ones:

> There's a patient who has been trying to have these conversations with her daughter for years. And the daughter's tendency is, "oh, you're talking ridiculous, you're not going to be dying." For family, it needs to get more objective than subjective. They need to see their parent losing weight, the skin breaking down, that they're not responding to them anymore. Otherwise, they make excuses, 'Oh, her pressure's not good because she's gotten too much blood pressure things; she's better in the afternoons than the mornings'; etc. I hear it all the time. And patients have a really hard time saying to their kids, "I can't do this anymore." They want to protect them, make sure they're okay; they don't want them to grieve. We try to give them allowance to say things they've said to us but aren't willing to tell family.

We spoke with only one family whose mother stopped dialysis in what would appear an instance of planned, proactive discontinuation. Even then, events did not transpire in a manner the family could see as deliberate. The ways they and the patient negotiated around "choice" and the timing of death instead reveal the uncertainty underlying such decisions and partly explain their subsequent invisibility. The patient's son and daughter-in-law described how their mother begged to be delivered from the responsibility of decision, and how they did, too:

> Every treatment, she'd ask, "why do you make me do this?" When her [access] failed, she started giving up. She wasn't super-determined… it was more, "I'm asking you to do this. I want you to make this decision for me." So we floated the idea, "This is your decision. You have ultimate control. Is [stopping] something you really want to do?" She'd back down, "Well, no." Up till the end, she'd say, "This is no way to live. You need to stop this." And we're going, "We need to stop what? We're not doing anything. What is it you want to **do**?" [Son:] Then, before Christmas, we saw the social worker and the first thing Mom said was, "I want to quit. I don't want to do this." I said, "Mom, you said you'd give us till the first of the year." The social worker got on her side, "Well, I think we should do what she wants." Meanwhile, I'm not asking her to give up what she wants; I'm asking her to postpone it two weeks. It was a long, ongoing thing. So, I don't know…when exactly the decision happened.

"The problem," a nurse contributed, is that "no one wants to take responsibility for saying no." Instead, doctors, families, and patients—none of whom "want to upset" the others by being "too explicit"—shift amongst one another responsibility for discussions and decisions about stopping treatment.

No one, it furthermore seems, wants to weigh in on the value of life. Clinicians (and family members) say it is "up to the individual," that "everyone is different," that it's about "quality of life," and therefore "subjective," "a mystery." For many patients, meantime, the value of life has shaded into the value of remaining alive—and the specter of death erases the possibility of deliberating the decisions surrounding it. Thus, we found that patients often resisted talking (or talking at length) about their experience of living on chronic dialysis, opting to remain linguistically and thoughtfully removed from the experience even while practically embroiled within it. "I don't like to dwell," emphasized a 73-year-old man in a manner typical of the patients with whom we spoke; "you do it, or you die. It's that simple." A nurse, commenting on the inevitability of death without dialysis, noted that reality effectively removes patients from the domains of deliberation and choice—as she phrased it, from "the realm of the qualitative"—and locates them in a "starker place beyond [value] judgments." "Your assessment of life isn't qualitative anymore," she noted of dialysis, "Once you're here, we're way past that. It's are you going to live or not, and most patients want to live."

Passive non-compliance

In our discussions with patients and clinicians, we documented a range of awareness and agency around the process of stopping treatment. While clinicians insist proactive discontinuation is uncommon, they acknowledge patients may “self-terminate” in oblique ways to avoid difficult choices, active deliberation about their situation, or upsetting discussions with family members. A social worker differentiated between “passive discontinuation” and the more “desirable course of dignified discontinuation”:

> It’s rare someone actively discontinues. I’ve had patients self-discontinue through passive-aggressive behavior. Patients who pull out their catheter, or it just keeps coming out. ‘Cause they can’t directly say, “I don’t want to do this anymore. Take out my catheter. Make me comfortable.” I’ve told patients, if you drink a gallon of grapefruit juice, you may have a heart attack. Yet they continue doing things like that. Then, there’s the conscious decision to discontinue dialysis which is: you’re in pain and you want to die at home with hospice. That’s a more beneficial route. Then you have the chance to say goodbye and resolve things you want to resolve.

Patients rarely discussed with us non-compliance with their treatment, although some described digressions from their prescribed diet or attempts to shorten or minimize treatments. A 72-year-old woman addressed the issue one day when asked how she was feeling:

> I’m waiting for death. Now, I can’t walk because of arthritis. So I’ve started eating whatever I want. Yesterday, I ate a mango and salted shrimp. My son says, ‘Mama, that’s not good.’ But I say, ‘I’m 72, I’m going to eat what I want. It’s not going to get better anyway. I’m so tired,’ I tell him. Fifteen years on dialysis, can you imagine? What have I got to live for? I eat, I go to the bathroom, I take a bath. I can’t do anything. I’m bored. I want to go home (to the Philippines), but I can’t afford dialysis there. The other night, I put $50 in my pocket and went out alone in my neighborhood in my wheelchair. It’s dangerous there! I don’t care anymore.

Events leading to discontinuation

When patients do discontinue treatment, it almost always occurs in the context of acute illness, generally following a long course of physical deterioration. A nephrologist described the process: “It will be that things are going okay, okay, then medical deterioration, things are going medium, medium, then acute medical deterioration, and then they just say, ‘Forget it, time to stop.’” Like that of initiation, the process is characterized less by the exercise of choices than the imposition of health exigencies that demand quick action. “It isn’t a lifestyle decision,” a nurse explained, “most get so sick, they wind up in the hospital and *it just happens*. Or the family puts a stop to dialysis because they’re so sick.” “Almost always, there’s a precipitating event,” added a social worker; “the patient is hospitalized with failure of another kind. And if they’re deemed significantly worse off than when they left the unit—maybe they’re no longer ambulatory, or they’re demented, or they’re not indicated for another treatment or procedure they need—then that might be a time those discussions come up.” Several clinicians noted the breakdown of patients’ access points for dialysis (where needles are inserted) as an event that can lead to discontinuation. A dialysis nurse outlined a hypothetical trajectory of occurrences that could prompt patients or families to cease therapy:

> Patients start ending up in the hospital. We’d ask, is it simply diet and fluid compliance issues? Or is it that your heart can’t take it? Or is there something else going on? You’re diabetic and you’ve not got your blood sugar under control? Maybe you’re having an amputation done, and you’ve had infections. Or you’re unable to maintain your access, that’s a big reason people fail. If you don’t have a good heart or blood pressure, those clog up. You can’t always open them… so then you’ve lost that access. Maybe you’ll try the other side. That may last a month or two. Then that clots off. You put in a temporary line. Lines are high risk for infection. So then you get infection after infection; maybe that’s why you’re coming to the hospital frequently. What do

> you do then? You've run out of space. You can't put another access in. And you can't have someone living in the hospital on antibiotics, sick all the time.

A fairly vigorous 72 year-old man did make the proactive choice to stop treatment; in contrast to the nurse's claim above, this was for him precisely a "lifestyle decision." Of all the patients with whom we spoke, this man most lucidly articulated his dubiousness about whether he would or should remain on dialysis. He insisted he felt more "wiped out" the days and weeks that he came to therapy than those he did not or came less. He was convinced, despite the protestations of dialysis staff, it was dialysis that was "killing him" and that, had he never started the therapy, he would be in better shape. He was not certain what to expect if he stopped but, deeply unsure he wanted to live any longer on dialysis, said he was prepared for the worst:

> Everyone tells me the same thing: I need to be here three days a week. I'm not convinced. I still feel great. Everybody here's been nice; I don't want to disappoint any of 'em. But I lived a good life for 69 years before this. And it's hard for me to accept I can't [do the things] I've always done. My life is gone now. So I'm thinking seriously about quittin.' They're all, "you can't do that. You'll die." But…[shrugs] … starting in April I'm gonna cut down to one day a week, see how that works for awhile, and whittle down. We'll see…

This man did stop treatment shortly after our interview. After several weeks and two heart attacks, he returned to the unit much frailer and "looking terrified," observed a nurse. "They made me come back," he said ruefully; "this machine has ruined my heart." He resumed dialysis twice a week (less than recommended), insisting it might be temporary. "He calls the shots," stated one nurse; "I respect that. You're the one who has to live with it. You need to take responsibility; do it your own way." Another nurse disagreed, noting the problem of such pro-activeness for a therapy that requires strict compliance for success. What is important on dialysis, she claimed, "is what you *do*, you keep showing up":

> Look, he keeps coming. Not regularly, but he's here today. Sometimes a patient will say, maybe I won't come in tomorrow. I'm tired. I don't feel like coming. And sometimes they don't. But then they'll come in the next day or two, which always interests me—because that means they're not really ready to stop.

Older patients' acquiescence to and amenable *participation in* treatment is construed by clinicians—for whom doing trumps talking—as a choice and *decision for* treatment. A reason clinicians cannot hear older patients' appeals that they do not want to continue dialysis is that those comments and their conduct seem not to jibe. "We seem not to hear [about discontinuation] much in the short-term care conferences," mused a social worker; "maybe because everyone is religiously coming to dialysis, we don't see them as wanting end of life discussions." That patients are seen to be "voting with their feet," as one technician put it, exacerbates confusion about their expressed wishes and words, and how seriously those should be regarded—an uncertainty illustrated by the ambiguous status of "Do Not Resuscitate Orders" in these units. The nurse director at one unit commented on the difficulty of interpreting such orders in the context of dialysis therapy where the presumption is that patients are "choosing life":

> Dialysis is a life-saving procedure. By going to dialysis, you are choosing to live. If you don't want to live, why are you going to dialysis? So it gets difficult in that… You're choosing one life-saving procedure called dialysis, but you don't want another life-saving procedure called resuscitation. So DNRs here are kinda soft. They're what the patient wants, yes. But in an out-patient setting, basically, we don't want to get to the point of a patient actually full-coding. Patient comes in, doesn't look good—send them to the hospital with their DNR. If they code there, hopefully they'll leave them be. But coming to the unit, they're de facto choosing life.

Choosing later

The attention to what is and appears, rather than what is said or implied, is striking in a therapeutic context overtly given to a rhetoric of patient expression, self-management and control, and yet in which many patients do not know or fully fathom what they have agreed to or what it would mean to discontinue treatment. It is notable that, in a situation in which patients perceive few if any choices, dialysis offers consummate control over the timing of death. “And then they give you a choice,” quipped one patient (82 years old) about the decision to start dialysis treatment, “you can die now or you can die later. I chose later.” For patients, the experience of “choosing later” is central to treatment. Several commented they preferred—if only as a matter of personal style—to think of themselves as “choosers.” “It’s the difference between us and animals,” explained a 70-year-old patient; “we have knowledge and free will; we can choose and act on that choice.” Said another, “I don’t *want* to be here, but nobody’s pushing me—and I still like to *think* everything’s my decision.”

For some patients, it is exactly their awareness they *can* decide to stop that makes the experience tolerable and keeps them coming to treatment. “It’s the only thing that makes it bearable,” stated one patient, who complained she had become isolated on dialysis, removed from family and friends by virtue of her schedule. “I’m not here by choice,” she emphasized. “It’s the result of blood tests. And there are times I think I’d like not to come—but then, I just keep coming back. I don’t know if I *will* quit voluntarily, but I like to know I *can*.” Indeed, patients who are hesitant about starting treatment may be offered the possibility to do so on a “trial basis,” with the understanding they can discontinue anytime they choose. A 76-year-old man spoke of the comfort he found in knowing he could “end things” if he became too sick or miserable. “I have this tremendous control,” he stated, referring to the possibility of staging his own departure, “one that people with cancer don’t have in the same way. Dr. ______ said I’d probably live three to thirteen days without dialysis, and that it could be made very comfortable for me.” He viewed the possibility of discontinuing treatment, should “it become too much,” as his “ace in the hole.”

Patients thus choose to be choosers… and they choose to choose later. “When I reach that point,” a 71-year-old patient often said, referring to other weak, long-term dialysis patients, “just shoot me.” That patient needed to maintain the idea of a limit of frailty beyond which she would not go. But that limit always exists in the future. The experience of dialysis treatment for many patients, then, is one of simply *not choosing to stop now*, in the face of the value of life at any cost and the promise of possible choice in the future.

Conclusion

Dialysis as long-term therapy for older patients renders problematic concepts of patient “choice” and “decision-making” that tend to dominate provider accounts about treatment initiation and discontinuation. Most elderly patients we spoke with do *not* want or choose dialysis. Neither, however, do they want to die. Most grudgingly accept treatment—at least for a time—until they become so sick or the burdens of treatment so profound that family or health professionals, mostly, initiate discontinuation from treatment. There are exceptions, and some patients talk proactively about ending treatment and/or take steps to do so. For the most part though, as we observed, older individuals question life on dialysis treatment; wonder when the treatment ends and how; remain confused about the goals of treatment and what to expect from their lives while on dialysis; and choose to authorize death later.

Patient confusion and dubiousness about the goals and ends of treatment have implications for their quality of life on the treatment and their relationships with clinicians. First, most older patients indicate they would like more information and communication about their prognosis, how long they can expect to be on dialysis, and what they can anticipate (or not) from a treatment that is not a cure. Second, as Ashby and colleagues (2005) illustrate, there is a dearth of established pathways to dialysis cessation and palliative care in most countries and centers. That, with time, there is a transition to be made from dialysis as “treatment” to end of life care could be better explained and managed to alleviate patients’ unneeded suffering and confusion. To the extent clinicians acknowledge patients’ questions and concerns when those arise, and discuss halting therapy, they may ameliorate the existential suffering and isolation their older patients on dialysis sometimes experience. In that process, clinicians may be able to facilitate decision-making either to continue or to stop in greater partnership with patients.

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