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“Is There Life on Dialysis?”: Time and Aging in a Clinically Sustained Existence

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Abstract

Increasingly, in the United States, lives are being extended at ever-older ages through the implementation of routine medical procedures such as renal dialysis. This paper discusses the lives and experiences of a number of individuals 70 years of age and older at two dialysis units in California. It considers what kind of life it is that is being sustained and prolonged in these units, the meanings of the time gained through (and lost to) dialysis for older people, and the relationship of “normal” life outside the units to an exceptional state on the inside that some patients see as not-quite-life. Highlighting the unique dimensions of gerontological time on chronic life support, the article

Keywords

death; medical technologies; kidney dialysis; American health care; old age

INTRODUCTION

For growing numbers of older individuals in the United States, life’s end is indefinitely forestalled through the routine implementation of medical procedures. The existential and social ramifications of medically delayed death are profound, pervasive, and only beginning to be understood. They include the displacement of ethical by technical concerns and approaches to decline; the reconceptualization and altered expression of kin and intimate relations; the contribution to a new life form in which death is increasingly brought into life;

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and the emergence as well of a new kind of time before death, one marked simultaneously by decisions and denial, anxious anticipation and active avoidance of life's close.

This paper draws on the experiences of persons age 70 and over in two renal dialysis units in California to consider the relationships between living and quality of life, dying and the awareness of (even the desire for) death, in this new kind of penultimate time crafted in the clinical postponement of death. One is an inner-city, hospital-affiliated unit with an ethnically diverse patient population including mainly African American, Chinese, and Russian-speaking patients, many of whom are financially compromised and have little social or family support. The other is a private dialysis unit, part of a chain, located in a well-to-do suburb and populated primarily by white, middle-class patients, as well as some Latino and African American patients, with comparatively high levels of family involvement. Patients over 70 years of age comprise nearly three-quarters of the census at the inner-city unit and over one-half of the patient population at the suburban unit. At both clinics, patients are living with multiple diseases, including, among others, diabetes, hypertension, cardiovascular disease, and metastatic cancer. Also at both, the issues explored below were equally present.

The work of life for many of the elderly patients who frequent these units has become simply, overwhelmingly, that of living— as life (and its indefinite continuation) is "assumed itself as a task" (Agamben 1998:153). The burdens of dialysis treatment for these people are, paradoxically, not only the *drain* on their time and resources (even as those are perceived already to be on the wane) but also the ways that dialysis *occupies* time—opens up and makes anxious time—as these patients apprehend no end to their treatment. In the ways that it consequently makes and takes, inhabits and empties time, dialysis threatens to overcome and, for some patients, to *become* the life that it extends, despite provider exhortations and patient intentions that this not be the case. In his writing on "bare life," Giorgio Agamben (1998:153) theorizes the political significance of life that, "lived beyond its value," becomes the "site of an incessant decision" about that value and thereby about its perpetuation or cessation. For many older individuals who undertake the daily rigors of long-term life support, dialysis is precisely such a site of decision.

Our inquiry into the normalization of long-term renal dialysis for older persons adds to our work on the formation of kinds of life near death, the institutional structures from which they emerge, and the categories of knowledge and experience they produce and destabilize. In the case of dialysis for end-stage renal disease (ESRD), we note first that the idea "end-stage" is routinely denied in the day-to-day approach to the disease and to treatment. The fact that death can only be avoided by sustained, invasive treatment— and that death is only a few days or weeks away if treatment is stopped—gives rise to a particular (and uncomfortable) sensibility that is unique among the growing array and reach of late-life-prolonging medical procedures. If one remains on dialysis, then death will gradually, insidiously fill up more and more of the experience of life, including more and more time, until life is finally forced to succumb to death. If one wishes an alternative scenario, one must choose, proactively, to die before an end in the unforeseeable future, which dialysis pushes ever forward in time. That is the existential, inevitable dilemma created by chronic dialysis for older persons.

Our goal is to remain close to the ethnographic details and to patients' own words and experiences of treatment as a way of portraying the phenomenological terrain of chronic hemodialysis among older individuals. Patient accounts, many of which highlight a lack of medical knowledge of disease and treatment, underscore some of the ethical problems posed by chronic dialysis among the elderly and complexify concepts of choice and decision making around initiating or terminating treatment. Here we describe how patients' and clinicians' working definitions and pragmatic activities regarding life and death create new forms of temporal subjectivity for older patients. Specifically, we consider three issues: (1) we describe the experience of dialysis in the words of patients, including their perceptions of restriction, diminishment, and altered time; (2) we highlight patients' ambiguous status relative to life, their sense of being between life and death, which is partially revealed through their depictions of the numbness and purgatorial quality of time spent on dialysis; and (3) we reflect on the relationship of this state of between-ness to the absence of discernible ends within this clinical arena and form of medical practice.

Older persons' accounts of disorientation and liminal experience in these specialized units constitute a shadow story to more dominant cultural narratives of "good death" and "dignified dying" that have coalesced in recent years around right-to-die initiatives and around the rise and gradual acceptance of hospice and palliative care practices. Maintenance dialysis, as a growing (but as yet largely hidden) phenomenon among elderly persons nearing the end of life, reveals a world of technologically sustained life and clinically prolonged dying that is not publicly articulated and that remains, even for those existing within it, not easily comprehended or expressed. In this indeterminate mode of being, the transition from "living" to "dying" is extended, sometimes by years. Time is divested of its prospective character as patients inhabit a "holding pattern" and as the distinction between life and death is obscured. For some patients dialysis therapy can appear to be a Sisyphean task, and they are forced to confront why they continue. Thus, for example, on one particularly despairing day an elderly man asked whether our research might answer his question: "Is there life on dialysis?"

THE GRAYING OF DIALYSIS TREATMENT

Renal hemodialysis is a process whereby blood is cycled out of the body and filtered through a machine, essentially an artificial kidney, which removes waste and excess fluids. Dialysis emerged in the 1940s and 1950s as a short-term, intermittent procedure for persons suffering from acute and life-threatening kidney failure. With the advent, in 1960, of long-term, or "maintenance," hemodialysis for the ongoing treatment of individuals with chronic, irreversible loss of kidney function, medical providers entered a "limbo-like area" in which they could sustain life indefinitely without curing the underlying disease (Fox and Swazey 2002). In the United States long-term dialysis opened the door to a host of now familiar bioethical dilemmas, including the availability and allocation of a new and costly therapeutic innovation and the practical and existential difficulties for patients and families of chronic life support. As Renee Fox and Judith Swazey noted presciently at the time, it was unclear whether the long-term procedure would constitute a blessing or "merely a labored and painful hanging onto life" (217).

With fewer machines than patients who would benefit from them, the question of how to adjudicate claims for scarce therapeutic resources remained paramount into the 1970s. Maintenance dialysis was in fact initially precluded for anyone over 45 years of age (Rothman 2003:150). Since the passage in 1972 of a public law extending Medicare benefits for dialysis to all individuals with end-stage renal disease, the criteria for dialysis selection—formerly stringent—have loosened and, over time, largely fallen away. At the same time, advances in dialysis care—for example, the development of a more durable and long-lasting fistula,[1] and better management of the anemia, nutrition, bone disease, and peripheral nerve disorders that affect dialysis patients—have meant that physicians are now more successful at dialyzing patients (including many older patients) with complicated and multiple disease states. These

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[1] Hemodialysis treatment requires access to the vascular system so that blood can be removed from and returned to the body. Access may be external (through a catheter in the neck, chest, or groin) or internal. Internal access is achieved through an arteriovenous (AV) fistula or graft. Fistulas, usually placed in the arm (sometimes the leg), involve the surgical creation of a permanent connection between an artery and vein under the skin that enables adequate blood flow for dialysis. They are the preferred vascular access for long-term dialysis patients because they last longer than other forms of access and are less prone to infection and clotting (American Association of Kidney Patients 2002).

combined developments have led to a treatment milieu in which physicians may consider dialysis potentially appropriate for all ESRD patients and, moreover, in which they may feel it is morally unjustified *not* to offer dialysis to any patient with ESRD. Consequently, ever older individuals are now routinely dialyzed in hospitals and outpatient treatment centers across the United States.

Physicians are apt to state that advanced age alone is no longer a factor in evaluating patients for dialysis; instead, other factors (albeit often age-related), for instance, dementia or co-existing life-threatening conditions, emerge as either indicating or eliminating criteria. Yet, even while shifts in the socio-economic and clinical arenas have increased the number of older persons eligible for dialysis treatment, questions about the appropriateness and duration of the therapy for older patients (who typically have greater systemic illness and poorer prognoses for rehabilitation and survival) and about “quality of life” as both a criterion and measure of treatment loom under the surface of practice.

Meanwhile, patients over 65 years of age represent the most rapidly expanding segment of the end-stage renal disease population in the United States as well as in Europe and Australia. Between 1977 and 1995 in the United States, the numbers of new ESRD patients ballooned from 16,000 to 72,000. In 1977, patients over 65 comprised 27 percent, and patients over 75 made up 5 percent, of the total number of new patients; by 1995, patients over 65 comprised 46 percent, and patients over 75 nearly 20 percent, of that total number (Brown 1999). So, too, has there been a progressive graying of the dialysis population. In 2001, in northern California, patients between 65 and 79 years of age made up 34 percent, and patients over 80 years made up 10 percent, of an overall dialysis population of 12,532 patients (Transpacific Renal Network 2001:16). And of the nearly 85,000 U.S. patients who initiated some form of renal replacement therapy (peritoneal or renal dialysis, or kidney transplant) in 1998 49 percent were at least 65 years of age, as compared to 37.8 percent of those accepted for therapy in 1990. Projected trends for the next ten years indicate a vast majority of new patients at age 65 or older, with an increasing proportion of those individuals being older than 75 years (Jacobs and Mignon 2002).

Even while dialysis stations are occupied by growing numbers of ever-older patients, the goals of treatment have not evolved from those of half a century ago to reflect this shift in the demographics of the patient population. Indeed, with few exceptions (Cohen et al. 2003; Davison 2002), the role of palliative care and acknowledgment of the nearness of the end of life in these settings has not been addressed in the medical literature, which instead indicates that clinicians are disinclined to discuss death with patients (Perry et al. 1996; Christakis 1999). The result is that many older patients find themselves stranded—not getting better but hoping also not to get worse, not fitting the ethos of treatment (which simply stresses that dialysis allows and extends life) but not yet within the ethos of hospice or palliative care. Unready to “choose” death, many of these patients are, even so, ambivalent about continuing treatment. That stranded space that we document here and that presents a phenomenological dilemma for patients in these units also, and ultimately, poses an ethical dilemma for all of us as we consider how best to care for the oldest members of our society.

“CHOOSING” LIFE (SUPPORT)

Central to the experience of dialysis treatment is profound confusion about how—through what trick of fate, through whose choice, through which exact chain of life events and medical circumstances—patients came to be in this particular situation. Uncertainty about how they got here is a theme that pervades our interviews with forty-three maintenance hemodialysis patients age 70 and over.[2] At times, as they struggled to translate their experience into words, it seemed to be through our interview conversations that older patients attempted to gain some narrative purchase over an experience many find entirely incomprehensible.

Only four patients interviewed expressed their initiation of dialysis treatment as a “choice,” or proactive decision. Indeed, many patients do not have a choice initially: they land in the hospital, extremely ill, not fully conscious, and they are placed on acute dialysis as part of life-saving medical treatment. “They just wheeled me down there,” said one patient, referring to the acute hemodialysis unit to which she was taken after her kidneys failed during open heart surgery. This patient, who had “never wanted to be kept alive by a machine,” emphasized her exclusion from the decision-making process: “The doctors pretty much made the decision and my son agreed. But,” she added pointedly, “he’s not the one sitting here now.” Somewhat surprisingly, the perception of “no decision” around dialysis also pertains to patients who did not experience a life-threatening emergency event and whose preliminary “pre-dialysis” conversations and education we witnessed in the nephrology clinic. Those patients agreed to be fitted for a fistula or graft (in their arm, to accommodate the dialysis needles), to talk to the dialysis social worker, and to start treatment.

The sense of dialysis as imposed, involuntary, even inevitable, results from several factors. First, for those patients who are referred to the pre-dialysis clinic, it arises from the gradual approach of their end-stage renal disease, in which clinicians prepare them over several clinic visits for the eventuality of treatment and accommodate them to the idea of living longer and well on dialysis. In these cases, patients will typically, if reluctantly, accede to the incremental steps and procedures that lead to dialysis—for instance, to the periodic blood tests that track loss of kidney function and determine the start of dialysis; to the insertion of a fistula (a relatively minor, out-patient surgical procedure), advised as a cautionary measure “should patients need or choose” to initiate dialysis at a later point; or to an exploratory visit to the dialysis unit. Discernible decisions about dialysis therapy for ESRD are pre-empted or made imperceptible by these earlier and comparatively unremarkable choices that anticipate and justify later treatment decisions—which are themselves often made at a point when patients are too ill, family members are too frightened, and the situation is too urgent to allow for a deliberate confrontation with the ramifications of initiating the procedure.

The (retrospective) evaluation of little or no choice about dialysis initiation emerges, second, from the utter unfathomability—from any position outside it—of the world of chronic life-sustaining treatment into which patients are heading. And it arises, third and most compellingly, from the bleak and starkly presented alternative to dialysis, which is death—and, patients are told, death in fairly short order, in a matter of days or weeks. The assumed certainty of death without dialysis trumps any risk-benefit analysis or “decision-making” process. “I had no choice,” “I wanted to live,” is what patients matter-of-factly report.[3]

In fact, many patients expressed only the slimmest understanding of how and why they came to be on dialysis or what exact condition(s) had led to their kidney failure. Many did not want

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[2] Ann Russ conducted all observations and interviews with patients and clinicians reported here in 2003–2004. The 43 patients interviewed ranged in age from 70 to 93 years. Twenty-six respondents were women and 17 were men; of those, 24 were Caucasian, 13 African American, 5 Asian, and one Latino. All interviews took place within the dialysis units while patients dialyzed. Because persons undergoing dialysis are often tired, nauseated, or (as treatment progresses) thirsty or prone to cramping, the interviews varied considerably in length and in depth; some were as long as two hours, while others were much shorter (sometimes fifteen or twenty minutes) and took place over several meetings. The location of interviews and physical disposition of those on dialysis could well have affected our findings and the kinds and quality of reflections patients made. Interview topics included, among others, patients’ experiences and decisions around initiating renal hemodialysis; adjustment to the therapy over time; impact of dialysis on patients’ lives and perceptions of aging and of death; role of the family in dialysis therapy and decision making; possibilities for exercising choice or preferences within therapy; perspectives on the long-term goals of treatment; and the circumstances under which discontinuation would be considered. All proper names utilized in the text are pseudonyms.

[3] See also Dickerson (2002), who similarly describes the sense of “no choice” among patients who have been implanted with an implantable cardioverter defibrillator.

to know or have to understand complex issues around, for instance, their creatinine levels or why potassium in their diet is bad for them. “I try not to think about it,” “I try not to dwell,” were typical responses to our questions. Willful avoidance and non-recognition of the medical dimensions of their illness and treatment appears to be one way that patients manage how much of their experience they are willing to give over to being sick and on dialysis. In response to our request to speak with him about his experience of dialysis treatment, one man stated emphatically, “Absolutely not. I don’t want to talk about it. I don’t even want to think about it. It’s difficult enough that I have to be here.”

Strikingly, some patients are not entirely convinced that they *do* need to be on dialysis in order to remain alive; they may not feel any better than before they started, and some insist they didn’t feel sick in the first place. Others—for example, patients who are still producing urine—are perplexed by the seeming discrepancy between their bodily experience and their diagnosis; if they are urinating, they ask, mustn’t their kidneys still be functioning? Nonetheless, they are told they must be on dialysis or that they will die, and they have no way to “test” this, they tell us, other than to risk death. “I’m still not sure they got it right,” said one patient, describing the urgent phone call he received following his first visit to the nephrologist informing him that he must start dialysis treatment right away. “No lead up, no discussion,” he said; “I’m also supposed to be a diabetic and, incidentally, I’m not sure I believe that either.” When asked how he is doing on dialysis, he noted that he “isn’t sure,” that although he feels the same now as he did before treatment, “they say I have to be here or I’ll be gone in two weeks.”

For those who cannot perceive themselves as being in need of treatment, it is enormously troubling to be “chained” to an experience they must “accept,” to be told that it is imperative that they dialyze on a certain schedule. Indeed, for some who did not feel sick with kidney failure, dialysis therapy—with its associated demands and discomforts—may be experienced as an exacerbation rather than as an alleviation of suffering. Five of the older men we interviewed questioned the irreversibility of their kidney loss and how doctors would know if their kidneys were to “rejuvenate” on the therapy. “I have no way of knowing what’s going on with me,” cried one 86-year-old man, whose words reflected the confusion and doubt expressed by other patients: “I can’t fathom it. I can’t look at my kidney, put it in my hand, and examine it myself. Why do I have to be on dialysis? What is kidney disease? How much of it [i.e., the disease] do I have to have before I need to be on dialysis? I ask these questions, but their only answer is to tell me to be here, to take water out of me. But that’s not an answer! I’m left dangling.”

“DOING TIME” FOR DIALYSIS, FOR LIFE

The experience of an altered sense of time is basic to the phenomenology of dialysis treatment. It is the theme that dominates our interviews as patients complain bitterly about the sheer amount of time occupied by their therapy and about the intractability—as one patient put it, the “inhumanity”—of the treatment cycle that many feel limits, even precludes, their life outside the unit. Bound to dialysis by fear if not by faith, and by the desire to stay alive, patients typically come to the unit three days a week (every other day) for anywhere from three to five hours on the machine. This is, for many, an exhausting process. One man compared it to having your blood run a marathon; another to a tug of war between the blood and the machine for the fluids that are being taken off. It can also be grueling to the extent that patients experience physical pain from being stuck by needles during treatment, or they experience nausea or cramps as fluids are taken off. By the time patients have waited for their transportation to the unit, have waited for their bay to become available, are weighed in and hooked up to the machine, and are finally removed from the unit and taken home, their treatment has taken the better part of a day. This is one of the key paradoxes of dialysis: that in order to extend your time, to have more of it, you must give it away, must have less (and a diminished quality of) time. Put somewhat differently, the treatment is a fundamentally sacrificial endeavor as, day-to-day, *lived time* is traded for Time proper, for *life-time*. In this way, dialysis is both a time-creating and a time-consuming process, one that in a way cannibalizes the quality of the time it creates.

Patients, without exception, convey deep frustration about the input of time required, about the fatigue and weakness they feel constantly (and especially on the days they dialyze), and about the fact that the therapeutic routine impinges on their time and restricts their activities and movement outside the clinic. For some, dialysis seems timed to maximally disrupt their lives or capacity to do anything else. “Having to be here three days a week is what I call a ‘command performance,’ “ commented one patient. “No sooner do I start feeling better [around mid-day the day after he dialyzes] than I’m anticipating coming back again the next day. But there’s no choice, no modifying the experience,” he added wistfully; “even twice a week would be completely different, but I’m told that’s not possible.” Gesturing to the tubes circulating his blood, another patient joked that he “can no longer travel any distance because [his] blood has to.”

Dialysis indeed instantiates a different formation of time (as of space)—one that is highly repetitive and circular, premised on the experience of confirmation and constant return, as many older patients tell us they live significantly and simply to return to dialysis. Patients will say that they feel “boxed in,” “trapped” by the experience, that they are on a “short leash” or that they’ve been given a “life sentence.” “I’m doing my time,” stated a patient one day, repeating an oft-used phrase. Comparisons with incarceration are rife as the cyclic nature of treatment both mitigates the progressive aspect of time—in effect, arrests time—and diminishes patients’ spatial horizons and reach. One man, who worked in prisons and on death row for many years, compared his dialysis chair, as his “last stop,” with the electric chair. Another noted, “I’m under arrest, and the sheriff is this box here (patting the dialysis machine), and that sheriff says ‘don’t leave town.’ “ In its aspect of being at once never done and constantly un-done as toxins build up in the blood between sessions, one woman commented that dialysis is “like housework, always waiting.” Another patient spoke with exasperation about the confining character of the treatment:

> I’ll give you another interview if you can answer this question: If I miss one or two treatments, how critical is it? It’s a legitimate question, but I can’t get a genuine answer. We’re threatened that if we miss a treatment the sky will fall. So, I’m asking you, if I miss a day, will the sky fall? I have no way to measure this. It’s only nine hours total each week on the machine, but do you understand that this is complete imprisonment, that it takes my whole life? I don’t want something for nothing. It’s just the time frames. Are there alternatives? Can I come two days a week? maybe three days in a row? I’m willing to write the check, but I’m asking, can I get on a different payment schedule?

Patients have various ways of dealing with the time-consuming and repetitive nature of therapy. In our small sample, we observed that the most difficult period of adjustment occurs in the first few months of therapy. Thereafter, some are more able than others to integrate dialysis within their lives. For one patient, this involves cooking dinner each evening for the daughter and son-in-law with whom she lives; for another, it means keeping up her garden, even when her “energy is low”; for yet another, a priest, it is achieved by continuing his ministry, through which he “stays alive” outside of dialysis. Indeed, a patient at the city unit one day insisted that dialysis needn’t be “lost time.” The challenge with “all time,” he noted, “not just dialysis time,” is how to make it “found”—which is to say, present and full—rather than “lost.” He uses his hours on the machine to read and to keep a journal and finds the time “instructive” to the extent that he must be more conscious of investing it with meaning.

For those patients who are relatively healthy, active, or socially connected, some are able to bargain; they will say that they “give three days” to dialysis and then “take four days for their life.” Two patients noted that they have negotiated with their physicians and, counter to advice, have altered their schedule to dialyze only twice per week. At least in terms of how they narrate their experience, however, such patients are the exception. Cumulatively, the testimony of older patients is that dialysis takes time but does not substantially fill it, that it makes exhausted and empty time as it drains their energies and capacities for life both inside and outside the unit. Patients (and often their families) thus remain ambivalent about dialysis therapy. On the one hand, it extends life and allows older individuals to persist; on the other hand, it is a “slow death” as patients live, in the words of several respondents, in a “holding pattern” and in the suspension of the inevitable.

NO END AND THE ENDS OF HOPE

Most older patients are not expecting, nor are they on the waiting list for, a kidney transplant. Thus, for them, there is no projected end to dialysis treatment. Nor then do they have the same incentive as do younger patients to demonstrate compliance, self-care, and activism around their ESRD. Instead, most can expect to be on dialysis until they die, although many express the “forever quality” of the treatment as only a dawning realization. The existential ramifications of chronic life support for elderly patients are therefore different from those for younger patients. Patients struggle to discern an end or outer limit to their situation. For example, they routinely asked how long older people can “last” on dialysis, what kinds of conditions or events lead to eventual decline on the procedure, and/or whether or not we know of anyone who has decreased their time or discontinued treatment and still lived.[4] “I want to get off dialysis,” emphatically stated an 83-year-old woman who had started dialysis two months before. “At the very least, I want to shorten it. I know 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?”

The manipulation and making of time, the prolongation, in other words, of “how long one can go on like this,” is a primary therapeutic aim. An intensive care nurse noted that the goal of dialysis is to “slow down time”: for the elderly, to decelerate to a “crawl” the ineluctable slide to death. Indeed, patients asserted that they “feel lethargic,” that they are in “slow motion” on dialysis, a therapy that makes naked the sheer effort of living for many who are older and frail. “I step out of the taxi from dialysis,” a 73-year-old woman said, “I look up the steps to my front door, and I know there’s only one way from here to there.” But “even to see it, to [contemplate] it, tires me,” she said. The experience of being made (to feel) slow in a world that is not, as patients register that dissonance when they leave the unit or when they confront their families and significant others, is one that emerges in various ways throughout our interviews. At the same time, some patients and families noted that dialysis speeds up time, that it accelerates aging. “Let me tell you about aging on dialysis,” one patient offered, reiterating the theme of our study: “you get old on dialysis. Your bones deteriorate, you get weaker. That’s aging. Dialysis, just sitting here day after day, accelerates everything.” The son of a patient at the city unit put it somewhat differently: “You see folks coming onto dialysis and they look healthy and rosy. Then over time, have you noticed, they all look the same? No matter how old they are. Their color is bad, they’re skinny, shriveled, wrinkled. Then they start coming in wheelchairs, with parts of their bodies missing. It’s like dialysis speeds things ahead to a point, then throws on the brakes … as if it makes everyone the same age.”

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[4] Official literature distributed by the National Kidney Foundation indicates that it is unknown how long people can live on dialysis and that it may be possible for some dialysis patients to live as long as people without kidney failure. Survival rates on dialysis depend on a variety of factors, including age, method and duration of access, and other medical conditions. At one clinic we observed, clinicians reported that one older man had been on dialysis nearly 20 years.

The question of how treatment then ends, and through whose agency, is one that hangs over the process and emerges often in patients' narratives about living on dialysis. Some patients wondered whether, if they did not reach a threshold to their willingness to undertake the treatment, the procedure might eventually reach its own limit of effectiveness or sustainability. "Now I have a question for you," a 92-year-old man at the suburban unit stated one day, after several visits during which we had discussed his difficulties adjusting to the treatment. "[My concerns] aside, do people reach a level of satiety, after which the treatment is no longer effective or maxes out, or after which they simply can't sustain it any longer?" Another patient, a woman 84 years of age who insisted that she agreed to dialysis only for the sake of her husband and son, asked when it would be permissible to "say enough." When, she continued, would she have "tried hard enough," "suffered enough," to have earned her death? She shifted uncomfortably in her dialysis chair as we spoke:

> The last hour is the longest. It's interminable. My butt hurts, my arm hurts, I'm trying not to move [in order to not jostle the needles]. Now they tell me I need to have the stent in my kidney replaced every three months. I didn't know this. Maybe I wouldn't have made decisions any differently, but I didn't grasp what the long-term maintenance would be. They do all these things to keep us going, and you wonder if you shouldn't just take some pills—and END it. I shouldn't complain … there's some who have it much worse than me. And I love my husband. At night, he reaches into the space between [our twin] beds, he touches my hand and tells me that he loves me. And I say "thank you for all you've done." I've been lucky … But I'm just so tired. How many years can this go on? When is the end of it [normally]? How long can [patients stay] on the treatment before they die?

The extent to which patients addressed such concerns with their clinicians is not clear. They would tell us that they did ask these questions yet received only vague or obfuscatory responses —for example, a shake of the head or a deferral of the topic to some later date (see Perry et al. 1996). Also possible is that patients did not like, did not trust, or simply were not convinced by the answers they did receive to their queries and, therefore, chose not to incorporate them. What is clear is that, aside from any discrete question and response between patient and clinician, or any one moment in the clinic when death emerged as a possible outcome of treatment (e.g., in patients' awareness of others' deaths), the overall trajectory and ethos of the treatment (framed as *life*-saving and *life*-prolonging) operate to deny and conceal ends— making those practically, if not linguistically, inexplicit. The focus is instead on "making live" (Foucault 1980; Rabinow and Rose 2003) and on patients' pragmatic and, over time, habituated efforts to present at the unit every other day. Death as the horizon of being thus recedes on dialysis as physical symptoms of dying are therapeutically masked and as ends are effaced by repetition and denied through the shared reluctance of patients and providers to acknowledge impending decline.[5]

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[5] This study both draws upon and departs from earlier works on the temporal management of death in clinical spaces, most notably those by Glaser and Strauss (1968; also, Strauss and Glaser 1970) and by David Sudnow (1967). Those seminal studies explored the "work" of dying in the hospital as well as one outstanding feature of the death trajectory: that it takes place over time, that it has a *duration*. Anguish among patients, according to Strauss and Glaser (1970), emerged through their awareness of dying, their experience of waiting for death, and, too often, their isolation (by hospital staff and, to a lesser degree, by family) within that interim. More recently, Sharon Kaufman (2005) has written of the "widely felt disquiet" that accompanies new capacities and technologies to control the timing of death in the hospital. The ability to delay the onset of dying—sometimes, it seems, indefinitely—and the increasing suppleness and susceptibility of the death trajectory to medical intervention and temporal manipulation, open new arenas of responsibility for patients and families who increasingly must authorize and "choose" (the time of) death. Kaufman notes that, because dying is only acknowledged in its most final stages, the "time of dying" in the hospital (and the "death-watch" described by Glaser and Strauss) has been radically truncated in recent years. This foreshortening is further intensified in dialysis units. Ironically, even while, in those units, the time of dying is made indistinct, the time of death in life—as living and dying increasingly shade into one another—is expanded for older patients. Regarding these issues of time and tempo at the end of life, see also Russ and Kaufman (2005) on the "pacing" of death in the hospital through the staging of prognostic disclosure in clinicians' communications to family members.

For many of the older patients (as well as for their families) there simply is no clear or foreseeable end to their experience of dialysis. Neither, however, is there an imaginable or postulated future outside of dialysis and how they exist now—which many see as not quite living. For if dialysis treatment is an experience of perpetual return (to the unit), it is equally, for older patients, an experience of the impossibility of return (to one's life or to who one was before or without dialysis). "There's no turning back," mused a 71-year-old patient, after having noted she was "against" dialysis when it was first raised by her doctor but was started on it nonetheless when she arrived at the hospital unconscious. Patients talk about how they have changed physically or about their inability to get back to certain pre-dialysis activities or interests, despite clinicians' assurances and their own hopes. "Do you know what the 'point of no return' is?" another patient, a Second World War air force pilot, asked one day. "It's the point where you don't have enough fuel to move ahead to where you're going and land the plane, but where you've also gone too far to turn back to where you came from. Well, you might say that I'm at the point of no return." This place, of emptiness or uncertainty ahead, and yet of irrevocable removal from what lay behind, is where many of these patients perceive themselves to be.

Hope, writes Vincent Crapanzano (2003:10–12), is located in the "dubitative future," the experience of not knowing what's to come. In its "invocation of an ever further horizon," he continues, hope is primarily defined by its anticipatory quality, its uncertain and unfolding manifestation. For many older individuals on dialysis, what Crapanzano depicts as the "not yet" of hope yields instead to a "not ever" of hopelessness as patients despair either of getting better or of getting off the treatment. Although treatment offers respite from impending death, the resulting loss of a sense of progress on dialysis is an aspect of the treatment that elderly patients continually emphasize as a source of distress. Patients expect such intensive therapy to result, if not in a cure, then at least in some obvious improvement or amelioration of their condition. "It's like time has stopped … it's the 'no progress' that I can't stand," a patient complained one day. Another woman echoed her comments:

> I don't know if I'm progressing or not. It's unclear. I know that I don't want to come here anymore, but I can't get a direct answer about that. The doctor shakes his head when I say it, but he doesn't say anything. I just want to know, based on my blood tests, am I progressing? Do they see a change? Any movement at all? A shift in those [results]? That's what I don't understand. Is there ANY change? … even if I have to stay on dialysis?

"With most other maladies," stated yet another patient, "one has some reasonable expectation of being cured or at least of some progress, but not with this one—so dialysis *is* a treatment, you see, but one with no cure, and no real tangible evidence of progress." He described a meeting with his physician:

> The doctor said to me, "Abe, you're doing so good." But there was no progress! No change in my condition for the better! I can see now that the best that I can hope for is for things to remain the same … that dialysis is about struggling to stand still, to stay exactly where you are—as the *most* that one can wish for. It was then that I realized I was going to have to give up on the dream of leaving here, of getting out of here. So that's that. I can live with this. I have no other choice. But let me tell you, I love walking out this door on Saturdays knowing that I'm sprung for two days.

"In many ways," that patient concluded, "dialysis is the end of hope."

For some, the hopelessness of dialysis appears related in equal measure to its temporal aspects —the ways it occupies time—and to the ways it denies patients a sense of progressive, palpable time—the ways, in others words, that it makes them "untimely": "estranged and de-naturalized from their own present" (Avelar 1999; see also Chambers 2004). Awareness of the passage of time is both diminished and heightened through the circular, rhythmic quality of the therapy as well as through the sensoria of the unit and of the bodily symptoms that accompany treatment. The monotony of the treatment shrivels time; indeed, patients sometimes show an astonishing insensibility to the passage of time over the course of their treatment. Very typically, when asked, they misstate by months or even by years how long they have been receiving dialysis; or they are entirely unable to provide that information and ask that we consult their chart or a nurse. The seeming endlessness of the treatment further contributes to patients' sense of being stalled, taken out of time—as do the physical spaces and white noise of the units that, without windows (at the inner-city unit), with the lights constantly on, and with the ceaseless whirring and beeping of the machines, are oddly hypnotic and intransigent to the outside.

The untimely aspect of the therapy is mitigated, however, as time is measured in the body, its duration discerned through the physical symptoms that mark the stages of treatment—the placement of the needles, the thirst that patients quickly feel, the nausea or cramping that may come up late in the treatment. And even while time loses some of its substantial character on dialysis, patients are acutely aware of its passage as they watch the clock and, while we speak, obsessively monitor the "TRD" (time remaining on dialysis) readings on their machines. Writing of tedium, James (1890:626) locates its emergence in that moment when "from the relative emptiness of content of a tract of time, we grow attentive to the passage of the time itself"—that is, when we become aware of the passage of time *as time*, as mere time. A patient one day alluded to this unalloyed perception of time when we discussed the potential benefits of his participation in a research interview. "You can't make time move any faster, can you?" he asked.[6]

BETWEEN LIFE AND DEATH

What does it then mean for elderly dialysis patients to live, in some ways, outside the notion of medical progress and in relation to an only indefinite future? In hospice settings, by way of contrast, dying and decline are given shape by the postulation of an end— and the possibility, even, of that as a welcome end—toward which patients, caregivers, and families strive in some concerted and conscious fashion. That end structures the time of waiting and creates certain possibilities for agency, intimacy, and community vis-à-vis a shared anticipation of death. Dialysis is neither contained nor compelled by a similar vision of an end or of acknowledged dying. As a more interventionist and non-teleological endeavor, neither is dialysis invested with the same kinds of narrative intention as is a hospice; rather, the treatment is viewed by most patients as simply "time spent," necessary but essentially meaningless, disconnected from a sense of purpose, and removed from the spaces of their lives and the sources of their identities that matter.

Agamben (1998) describes the "state of exception" as one in which a temporary abrogation is made steady, offered spatial expression, so that the extraordinary becomes indistinguishable from the norm. He ponders, in this regard, the mingling of life and death and how we might consider the status of the living body that "seems no longer to belong to the world of the

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[6] It is striking that such a temporally oblique clinical site as the dialysis unit—one not guided by the imperative, as Kaufman (2005) writes of the hospital, to "move things along" but, rather, by the attempt to find and maintain a "stable," still state for patients—should be spoken about by patients in primarily temporal idioms. On these issues of time, its perceptible movement and "progress," see also Linda Layne's (1996) analysis of her family's experience in the neonatal intensive care unit, where their expectations—shaped by cultural narratives of linear progress that are so pervasive in clinical and technological settings, yet simultaneously negated by what actually happens there—were constantly challenged by the "cyclical" and roller-coaster" nature of their stay in the hospital. Caroline Bledsoe (2002) also discusses how Western notions of fertility and aging are framed in terms of linear chronicity, whereby time is understood in part as "nature in the body." In dialysis settings, by contrast, bodies are oddly detemporalized, made "unnatural," as they are sustained and prolonged by a technology that incites ambivalence precisely on the ground that it attempts to transcend the limits of time, unsettling our notions of the "natural" progress of time and aging (Bledsoe 2002:18).

living" (e.g., those persons in long-term coma). Chronic dialysis, as a site of prolonged outpatient life support, could certainly be characterized in such terms. There, in a state of suspension (clinical, temporal, narrative), between-ness becomes the norm of experience as death comes to occupy considerable experiential space and as the relationship between the treatment and the life it both supports and constrains is conceived and negotiated.

Patients' liminal status is made graphic during the procedure of hemodialysis itself as the burden of maintaining life is shifted to the machine that regulates their blood pressure while they dialyze. Patients hold as still as possible during that time (in order not to dislodge their dialysis needles); typically, they doze, watch television on their private screens, or, as many put it, simply "zone out." Several complain that they "go numb" in the chair, particularly in the last hour of treatment. "I feel like Laocoön," commented a 93-year-old patient (referring to the Greek god bound and ultimately strangled by the coils of sea snakes) as a nurse reattached the tape securing his arm to his dialysis chair. Said another patient, a 78-year-old woman, conveying her sense of being a spectator to her own slow decline: "What can I say to you? I'm a captive audience." Yet another patient claimed that she considered herself to be in a "semi-coma" during her time on dialysis: that she "just goes on auto-pilot" and "then comes out the other end" when it's done. The ideal experience of dialysis for many patients, it seems, is really no experience at all—to have it affect your life and time to the least extent possible—that it should be withstood, gotten through, tuned out, forgotten.

The relationship between patients' considerable time and experience on dialysis and their lives and identities outside the unit is, meanwhile, a complicated one. While most patients view treatment as a departure from, indeed as a drain on, their "real lives," so too do they recognize that treatment enables life, is necessary for life. The tension between dialysis and the life it extends finds expression in patients' claims that dialysis is "no way to live," while the supposition that dialysis is intended to assist and to support life but not to *be* life, to *become* patients' lives, finds corresponding expression in clinicians' appeals that patients make dialysis "part of their life, but not all of it." This call to action and responsibility for maintaining one's own life outside of the unit can be a tall order even for younger and for the more fit and motivated patients who confront the challenge of how to remain vital in this situation of chronic passivity and enforced dependency. It is uniquely difficult for older people for several reasons. Many have outlived their peers, even their children. Their world is further diminished as some lose their sight, fingers, toes, or limbs. Mobility is also decreased for those in wheelchairs or otherwise incapable of walking any distance. And experience is deprived through dietary restrictions and through the "unimaginable thirst" that assails patients (who must limit their fluids), especially when they are dialyzing. "I'm dying in pieces," one patient diagnosed, showing us her dead fingernail, and then noting the lost function of two of her fingers, the toes she's lost, and how she's now adjusting to the below-knee amputation of both her legs. "I have everything wrong with me," she said, "but I keep going." She compared her experience of illness and treatment, both in dialysis and through her successive amputations, to that of a plant that must be pruned, the dead or dying parts excised in order to maintain the parts that are living.

Some patients, reduced to the "zero point" of their own capabilities (Agamben 1998:51) and yet still existent, feel themselves to be in a truly desperate condition. They question why, to what end, they are still here. An 84-year-old woman cried as we spoke: "I look at the other old people here [gesturing to the unit], and I ask, 'why are we here?' I guess it's not our time yet, but … [crying, shaking her head] I don't know why I'm here. I wish I could go. My husband doesn't like it when I talk like this, but I think, *why*? What good am I? I can't do anything. I can't even pee! I pee mud. My hair is gone and I can't get out by myself to get a wig. I look in the mirror, I don't recognize myself. I itch all the time, I can't sleep … why, why am I still here [crying]." Others feel that they are already, in significant respects, departed, irrevocably altered, or at a remove from life. “I wake at night, and say out loud, ‘I’m gone, I’m dead, ‘ “ said another patient and double amputee who, in previous conversations, had expressed feeling “stranded alive,” without family, without legs, with overwhelming debt, and without any sense of possibility for the future. “It takes you away from life for so much of the time,” commented another patient whose most significant social interaction remains with her brother, now dead three years, whom she misses terribly and with whom she claims to speak at night.

Patients’ intimations of decline emerge also from the fact of living in a unique kind of close temporal proximity to one’s possible death. In support group one day a younger patient described in compelling terms what it means for him to live, as he put it, “always within two weeks,” and therefore keenly aware, of his own death. “You *seem* to belong to the living,” he considered out loud. This sense of only appearing to be fully or functionally alive is exacerbated for some by the incommensurability of their existence inside the unit—during which time they are separated from the world and from life (or only instrumentally attached to it) for long periods—with that outside. One patient referred to dialysis as a “shadow life”—one that he claimed can overtake “real life”—and in that respect compared the experience to an affair: that dialysis is removed from everyday life, mainly invisible, unknown and untranslatable to others, yet that it takes up so much of one’s time, thoughts, energies.

The feelings some patients have of being between life and death, as perhaps already promised to death and awaiting fulfillment of that promise or even of living in an afterlife, were expressed explicitly one day when a Roman Catholic priest who dialyzes at the city unit spoke about purgatory, which he described as “heaven’s waiting room.” “Purgatory is about the cleansing and purification of the spirit,” he said; “it is the opening of the door to the afterlife.” Dialysis, he went on to suggest, partakes of a purgatorial logic and occupies a similar and unique temporal and spatial structure—as an intermediary space of cleansing and waiting before death. For him, and he is unusual, this makes it spiritual time and, indeed, he uses the time to read, to pray, and to prepare homilies and prayer group discussions. Jesus went to the desert, he conveyed, a place of desolation and quiet but also of reflection, because it was there that he could hear God’s voice and speak with him. “Dialysis is like a desert for me,” he said.

Perhaps it is because the experience of dialysis itself lacks clear intentional or narrative structure that patients sometimes attempt to reimpose that structure through religious (and often resoundingly Christian) themes. A patient who had been reading the 23rd Psalm one day questioned whether we might determine if she was “living in the valley of the shadow of death.” She concluded that this valley—composed of treacherous ground, defined by risk as well as by the absence of a clear future, experienced as “waiting for the good shepherd to come”—is exactly where she felt herself to be. Subsequently, two other patients also spoke of that psalm and of their being already departed, in the shadow of death.

CONTEMPLATING DEATH

For those older patients who sense they occupy an uncertain status, something between life and death, being on dialysis involves living in a kind of twilight time. The problem, then, of how this experience does end—of how, out of this indefinite prolongation of life, patients do come to die—is a crucial one for patients and clinicians alike. For though some patients perceive themselves as not wholly alive on dialysis, they certainly are not dead. Neither do many voluntarily choose to discontinue treatment. Moreover, every effort is made to keep patients alive during the treatment itself; blood pressure is monitored assiduously to help assure that patients do not “bomb out” or “crash” in the unit. A social worker, describing an older patient’s death on the open unit, emphasized how traumatic such a death is to the other patients and how much it is to be avoided. “We are not a life-saving unit,” she noted, articulating the professional discourse, "but of course that's not true. In fact," she continued, "you can't die here, there's not even a doctor here regularly who could pronounce you dead."

Over the course of therapy that can go on for years, death nonetheless occupies progressively greater experiential space for patients. In addition to "standing still," the experience of life on dialysis for many patients is thus one of "slipping." "Nothing gets any better, there's never any improvement," cried one 86-year-old patient who had just returned from months of rehabilitation following a double amputation, "and now, I'm losing ground." When patients become more debilitated and dialysis more clearly their central preoccupation, when the question of life's value is gradually and then more powerfully raised, patients are sometimes forced to confront their continued participation in treatment. A 73-year-old patient evoked the paradoxical circumstance of many older patients, who do not want to be kept alive (and dependent) and yet do not want to die:

> Dr. —— told me straight, "You're in an environment of death." I have to accept that. But I didn't like hearing it. Now with death, there's something you don't talk about, you don't want to think about, and we don't know how to prepare or handle it. So when you come into a situation like this, it's horrifying. And then you have to see other people go through the pain. ALL the time. And it breaks your heart. And you get close to these people. So dialysis is treatment, but just to prolong your life. And it's giving, I think, false hope. Because you think you won't die on it, but that's not true. Things can happen at any time to anybody. When your blood pressure goes down, you can go into a coma just like that. And they wouldn't catch it right away. I've seen that happen many times that they weren't able to revive the patient. If that were to happen to me, if I get to the point where I'm so incapacitated—in my living will, and my girlfriends know this, I don't want to be kept alive. I don't. But I don't want to die. But I definitely … I don't know how you do it though. I talked to the doctor about it and said very clearly what my wishes were. He said that I was the first [of his patients] to bring that up on my own.

Studies indicate that around 20 percent of dialysis patients each year, mostly over age 65, withdraw from dialysis treatment (Perry et al. 1996; Cohen et al. 1997; Cohen 2003). But just how proactive these decisions about withdrawal are, where and when they occur, and at whose initiation are questions not easily answered. Most withdrawal of treatment occurs in the hospital following an acute illness, when death is clearly imminent. Only three patients we interviewed addressed the topic of treatment discontinuation without prompting. One of these, a 71-year-old man, stated that discontinuation is his "ace in the hole" should the difficulties and rigors of treatment become too much for him. Some clinicians and at least two patients meanwhile suggested that there are various ways to "discontinue" treatment and that, for example, eating or drinking whatever you want, not coming to dialysis as scheduled, or not staying the full time could all be more or less subtle mechanisms for achieving that end. A nurse contrasted these methods with "dignified discontinuation," which, for her, meant the expressed consideration and conscious choice to end treatment.

Remarkably, given the burdens of treatment that patients emphasize, most were reticent on the topics of treatment discontinuation and death and, furthermore, recalcitrant when these areas of questioning were raised. We found that, during the routine course of dialysis in the maintenance unit, people do not necessarily want to talk or to think about when they are going to have to give up on dialysis, that this is an area at the end of life where one must in fact tread lightly. For example, a 73-year-old patient in the final stages of lung cancer chose to leave the city unit (to dialyze at a private facility) when she suspected that her nephrologist may have raised the possibility of dialysis discontinuation with her oncologist. The oncologist had encouraged her to consider whether the procedure, which she found draining (and the transport back and forth to the unit arduous), was any longer yielding the benefits and quality of life she wanted. Her response reveals some of why discontinuation— and why “ends” generally—are so exceedingly difficult to bring up with patients:

> My doctor wants me to commit suicide! I can’t do that. I can’t give life, only God can give life. And I’m putting my faith in Him up there. 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? to his children? And then he asked if I were to have a heart attack and I was on dialysis, would I want them to revive me? What’s this about a heart attack [crying]?! I’m very hurt, very hurt.

Most patients, indeed, express the desire to remain alive. During the period of our observations, a “quality of life” study was conducted at the city unit. Patients were asked to consider, hypothetically, whether they would choose one year of good health without dialysis or five years as they are now, on dialysis. Everyone who discussed this with us—including patients who had complained vehemently about the treatment, about their life and loss of life on dialysis, about their inability to perceive an end—chose the five years, though not without some deliberation. “I really had to think about it,” said one elderly woman, “and I pictured myself with legs and able to walk—and oh [dreamily], it was so wonderful.” “Why do I want to live so long?” she asked. She then answered her own question: “I guess I want to see what’s going to happen.” “That’s right,” contributed another patient, “We want to see what happens.” Another patient, commenting on the same study, insisted that it was precisely through his feeling of being “removed from life” on dialysis treatment that he was made aware of his own strong “attachment to living.” In other words, exactly as his quality of life was diminished, so his attachment to life grew.

For the most part, though, questions about life and its value are kept at bay, preempted and practically denied by patients’ ongoing participation in the treatment. And for most patients, it is simply too overwhelming to engage the big questions of meaning raised by these technologies and their capacities to extend and to alter life. Thus, patients rarely talk about “quality of life,” despite the currency of the term among clinicians who are inclined to raise it in discussions about long-term goals of care or shifts in patients’ functional status, often in lieu of (or as a proxy for) more direct discussions of death. For patients, though, for whom life has been purchased with quality of life; for whom the value of life has become largely, thereby, the value of living; and for whom that value intensifies as death nears, the concept seems to hold little meaning. It is, in fact, mooted through the process of treatment itself: life simply is —becomes—dialysis, and most patients choose to continue rather than to stop.

LIFE RE-EXPERIENCED

For many elderly patients on dialysis, treatment seems, in significant respects, misconceived. The service is cast in a curative, instrumentalist mode. It stresses compliance and activism in the pursuit of life (and in the hopeful eventuality, for some, of transplant). Yet this emphasis is a poor fit for most elderly patients who are concerned neither with compliance and activism toward the future nor, for that matter, with the embrace and conscious anticipation of the end (as in hospice) but, rather, with some kind of negotiation in and with the present to make life on dialysis acceptable. A technician alluded to this one day, noting that many older patients on dialysis are “in one of two places.” At the beginning of treatment, he said, they have “not adjusted”; they do not see dialysis “as their life, how they want or need to live.” For those patients, treatment is a “vicious circle” (he drew a circle, broken into three arrows). But for some patients, he said—typically those with “more schooling” or “with a family”—”they can find acceptance,” making dialysis “part of their life, not an obstacle” (he drew a complete, closed circle). “Most don’t reach that stage,” he said; “and they die earlier.” At some point, of course, one can negotiate no longer or one finds oneself in an increasingly poor negotiating position, and it is at this point, conceivably, that one must prepare for life’s end. But this is something for which the clinical culture and structure of dialysis treatment prepares patients only very rarely.[7]

The patient who posed the question “is there life on dialysis?” offered his own response a few weeks later. His answer to the question confirmed some of the technician’s comments. “There is life on dialysis,” he told us. “IF,” he added, “you are willing to change yourself and your expectations. IF you are willing to recognize yourself as you are rather than as you hoped to be.” While dialysis had initially appeared as a “kind of death” to him, he continued, it had, over time, become a “kind of life,” just a “different one” than he had known before. “You have to rise above it, otherwise it will crush you,” he continued, “for most people, they can’t do that, and it’s death in life.” Another patient echoed this idea: “I struggled with it, and struggled with it,” he said, speaking about his early weeks on dialysis and, in particular, adjusting to the food restrictions. But one day, well into his dialysis treatment, while one of the techs was hooking him up to the machine, the patient stated out loud, “This is my life.” The technician looked at him and agreed: “Yes,” the tech said, “this is your life.” “Just hearing that aloud gave me a strength and conviction I hadn’t felt before,” the patient reflected. “And since then, it’s been easier for me, even controlling my food as I must.” “Sometimes,” he concluded, “the words come first.”

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[7] A notable exception is the groundbreaking work of the Renal Palliative Care Initiative (see Cohen, Germain, and Poppel 2003; Poppel, Cohen, and Germain 2003; Spital, Cohen and Germain 2004).

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