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## Achieving a person-centered approach to dialysis discontinuation: An historical perspective

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### Abstract

In this essay, we describe the evolution of attitudes toward dialysis discontinuation in historical context, beginning with the birth of outpatient dialysis in the 1960s and continuing through the present. From the start, attitudes toward dialysis discontinuation have reflected the clinical context in which dialysis is initiated. In the 1960s and 1970s, dialysis was only available to select patients and concerns about distributive justice weighed heavily. Because there was strong enthusiasm for new technology and dialysis was regarded as a precious resource not to be wasted, stopping treatment had negative moral connotations and was generally viewed as something to be discouraged. More recently, dialysis has become the default treatment for advanced kidney disease in the United States, leading to concerns about overtreatment and whether patients' values, goals, and preferences are sufficiently integrated into treatment decisions. Despite the developments in palliative nephrology over the past 20 years, dialysis discontinuation remains a conundrum for patients, families, and professionals. While contemporary clinical practice guidelines support a person-centered approach toward stopping dialysis treatments, this often occurs in a crisis when all treatment options have been exhausted. Relatively little is known about the impact of dialysis discontinuation on the experiences of patients and families and there is a paucity of high-quality person-centered evidence to guide practice in this area. Clinicians need better insights into decision-making, symptom burden, and other palliative outcomes that patients might expect when they discontinue dialysis treatments to better support decision-making in this area.

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In a 1960 article in *Harpers' Magazine* entitled "The Patient's Right to Die", Joseph Fletcher spoke of the moral challenges posed by "the marvels of medicine," which included "cardiac pacemakers, artificial respirators, kidney dialysis, vital organ transplants, antibiotics, intravenous feeding."<sup>1</sup> He spoke of how these technologies were already starting to transform the dying process, and reflected on how in the recent past "when the point of death was reached, there was usually nothing that could be done about it," now patients could be kept "alive" long after "what would have been the final crisis."

This same year, the invention of the Scribner shunt in Seattle, Washington made it possible for patients dying of kidney failure to receive ongoing treatment with maintenance dialysis.

Once it became clear that it was possible to live for at least a year on dialysis and achieve a reasonable quality of life, Belding Scribner and colleagues at the University of Washington turned their attention to making this experimental treatment more widely available. Efforts to expand payment sources for dialysis were initially met with some skepticism: Should the costs of an experimental procedure really be borne by society? Had the benefits of dialysis been exaggerated and the harms downplayed by its proponents? Might a substantial investment in dialysis facilities be wasted if advances in organ transplant eventually made it possible for most people with ESRD to be transplanted?<sup>2,3</sup> Reflective of this ambivalence, funding for dialysis would remain spotty for the next decade. As Christopher Blagg recalled<sup>4</sup>:

“In 1961, because 3 of the original patients had survived for a year, Scribner asked University of Washington Hospital administration about starting more patients. They refused, concerned that if his NIH funding ever dried up, the state of Washington would have no choice but to continue to support the patients. Scribner then approached James Haviland, President of the King County Medical Society, to enlist community support. With Haviland’s help and a grant from the Hartford Foundation, the world’s first out-of-hospital non-profit community outpatient dialysis center was established in the basement of the Swedish Hospital nurses’ residence.”

From its inception, the most controversial feature of the Seattle Artificial Kidney Center quickly became its selection policy. Because of funding limitations, the supply of dialysis machines (and the staffing and infrastructure needed to deliver the treatment) was soon outstripped by growing demand from patients with advanced kidney disease who would die without treatment. The morally difficult task of deciding how to allocate limited dialysis resources among these patients was a prominent concern within the nephrology community at the time.<sup>5</sup> In 1962, the American public also became engaged with this question when an article appeared in *Life Magazine* exposing the ethically unjustifiable strategy that the Kidney Center was using to ration dialysis based on candidates’ “social worth,” (eg, their jobs, family responsibilities, position in society).

In contrast—and perhaps not entirely by accident—the medical literature in the 1960s was largely silent on the matter of stopping dialysis. As Renée Fox and Judith Swazey have suggested, the focus on technology and the rapid pace of medical innovation at the time contributed to a “death is the enemy” orientation and “a relentless refusal to accept limits.”<sup>6,7</sup> In his 1964 presidential address to the International Society of Artificial Internal Organs,<sup>5</sup> Scribner’s response to critics who saw life on dialysis as a fate potentially “worse than death” is emblematic of the kind of therapeutic enthusiasm this mindset could engender<sup>5</sup>:

“Chronic dialysis could be used to permit every uremic patient to die a most dignified death instead of dying the slow, agonizing death that characterizes terminal uremia. Most of the people here know from grim personal experience that death from uremia can be one of the most horrible known.”

In this address, Scribner predicted much of the controversy that would later coalesce around “deselection” (dialysis discontinuation). Although stopping dialysis treatments had not been

something his center had dealt with, Scribner saw this as a potentially much thornier problem than selection:

“Overt termination of treatment is so unpleasant a subject that many physicians would rather not even mention it; and yet, when we are dealing with expensive treatment to sustain life by means of artificial organs, the question eventually must arise. The problem is where to draw the line, what criteria to use and to whom to turn to make such a difficult life and death decision.”

## 1 | DIALYSIS DISCONTINUATION IN THE 1960S

One of the earliest descriptions of dialysis discontinuation appeared in a 1965 article in the *Annals of Internal Medicine* by George Schreiner and Jack Maher in which they described their experience dialyzing the first 10 patients at Georgetown Hospital in Washington, DC.<sup>8</sup> Two patients had voluntarily withdrawn from treatment, one because he “thought he was dying slowly, without dignity, and leaving an unpleasant memory for his teen-age children as well as intemperate demands on their sympathy, attention and devotion,” and another because he “felt discouraged at the realities of the program and did not desire a prolongation of what he considered ill-health.” Rather than recognizing that dialysis was not a good fit for either of these patients, the authors instead wondered whether they should have done more to keep them on dialysis and framed the question before them as whether patients should be “permitted to withdraw from the dialysis program.”

Despite these early descriptions of how burdensome dialysis could be for some patients, discontinuing treatment continued to have strong negative moral connotations. In a 1966 article in the *Annals of Internal Medicine*, Sand et al attempted to characterize patients’ “adaptation” to dialysis. Those who had “adapted” poorly were characterized as: “‘showing lack of motivation to be a productive member of the community’, ‘high strung, gets extremely upset,’ ‘very apprehensive,’ ‘periods of depression and poor work record’.” On the other hand, those who had “adjusted” more successfully “differentiated from the less adaptive patients in showing (a) higher intelligence, (b) a less defensive attitude about admitting to anxiety or emotional difficulty, (c) less reliance on emotional defenses that involve the use of physical symptoms (eg, hypochondriasis and hysteria), (d) more satisfactory emotional support from family members.” The parallels with the kinds of moral judgments that had guided the Seattle Artificial Kidney Center Committee’s selection process will not be lost on those familiar with Ms. Alexander’s Life Magazine article. Indeed, from the authors’ perspective, characterizing patients who had not adapted well was valuable precisely because it could help to inform the selection process by identifying those poorly suited to dialysis.

## 2 | DIALYSIS DISCONTINUATION IN THE 1970S

Some authorities even conflated withdrawal from dialysis with suicide. In October 1971, Abram et al published their controversial paper entitled “Suicidal Behavior in Chronic Dialysis Patients.”<sup>9</sup> The article described what appeared to be an extremely high suicide rate in the dialysis population, 400 times higher than for the general population, although many of the patients considered to have committed suicide had in fact died due to

“noncompliance” with, or “withdrawal” from, dialysis treatment. The timing of publication—as Congress was poised to pass legislation that promised substantial public funding for dialysis—prompted several angry letters to the editor expressing concern that the publicity the article had received might serve to derail this legislation.

In 1972, amidst widespread sentiment that rationing health care should not exist in one of the wealthiest nations in the world,<sup>10</sup> Congress voted to approve an amendment to the Social Security Act establishing the Medicare ESRD entitlement program,<sup>10</sup> which would greatly expand the number of patients eligible for dialysis treatment. Following this landmark legislation, more reports of patients dissatisfied with life on dialysis and expressing a desire to discontinue treatments started to appear in the literature.<sup>11</sup> In a 1976 article in the *Journal of the American Medical Womens' Association*, Tiah Ann Foster described the characteristics of patients enrolled in the Seattle program who had not “adjusted” well to dialysis.<sup>12</sup> She cited four reasons that patients might decide to discontinue dialysis, including that they “wish to manipulate others,” “have strong conflicts about dependency,” “wish to commit suicide,” or “reject the life-style that involves use of a machine.” It was felt to be important to identify those at risk for stopping dialysis because “when one patient threatens discontinuance other patients on the ward pick up the idea by ‘contagion.’”

### 3 | DIALYSIS DISCONTINUATION IN THE 1980S

By the 1980s a more enlightened approach to dialysis discontinuation was beginning to emerge. This was likely informed by a growing body of case law that generally upheld patients' right to autonomy, changes in the societal approach to end-of-life care (the Medicare Hospice benefit was established in 1982), and social movements focused on social justice and consumer rights. Together, these helped build a consensus around the importance of the patients' perspectives and values in shaping treatment decisions.

In 1981, Rodin et al described the characteristics of 80 decedents who had been on dialysis, 58 of whom had continued dialysis treatments until death, 21 of whom had discontinued treatments before death, and 1 of whom had committed suicide.<sup>13</sup> In this article, the authors drew a distinction between situations in which the impetus to discontinue dialysis had come from staff (n = 14) and those in which the patient drove the decision (n = 7). This article struck a decidedly more sympathetic tone toward dialysis discontinuation than earlier articles. For example, in describing the experience of a woman who wanted to discontinue dialysis treatments and ultimately stopped coming to dialysis when staff were not supportive, the authors noted:

“It seemed that discouraging the patient from deciding about the treatment at this early stage simply caused her to stop verbalizing her feelings. Ultimately the covert pressure to continue which she experienced from the staff prevented her from working out her decision with them. It seemed that it was only when she was out of the hospital that she could assert her own wish to discontinue treatment.”

Rodin et al went on to outline a framework for approaching decisions about discontinuing dialysis that was prototypical of contemporary approaches. For patients who were voicing a desire to stop, the authors recommended evaluating their decisional capacity, eliciting

reasons for wanting to stop and addressing any underlying psychiatric illness. In situations where there was a team decision to stop dialysis, the authors recommended presenting prognostic information, taking a proactive approach to eliciting patients' preferences around discontinuation while they still had decisional capacity and reaching out to bereaved family members after the patient's death.

In the mid-1980s, the *Journal of General Hospital Psychiatry* published the first case report of a patient who was supported by his physicians after he had decided to stop dialysis.<sup>14</sup> Shortly thereafter, the *New England Journal of Medicine* published the first systematic case series of patients who had stopped dialysis.<sup>15</sup> In this seminal article, Steven Neu and Carl Kjellstrand described 1766 patients who entered the dialysis program at Hennepin County Medical Center in Minneapolis between January 1, 1966 and July 1, 1983 and were followed through July 1, 1984. Of these, 155 (22% of deceased patients) died after dialysis was stopped and before a biological cause of death had "supervened." Most of these patients had dementia, stroke, or a catastrophic acute illness. Mean survival after the last dialysis treatment was 8.1 days (SD 5.3, range 1–29) and 13% died at home.

Although published more than a decade after the creation of the Medicare ESRD entitlement program, this article nevertheless inspired several angry letters to the editor expressing concern about the seemingly negative portrayal of dialysis, belying persistent in-security about public support for the treatment. Gerald Dessner (representing the New York Chapter of the National Association of Patients on Hemodialysis and Transplantation, now the American Association of Kidney Patients) expressed concern that by publishing these findings, Neu and Kjellstrand had "caused harm to new patients on dialysis and patients on long-term dialysis, and in addition, gave the general public the impression that therapy for renal failure is not worth the Medicare expenditure of more than \$22 billion." Echoing public concerns that the medical community might be basing treatment decisions on moral judgments, Dessner went on to suggest that the authors "focus their efforts on improving patient care and not on studies that offer no solutions except the restriction of renal therapy to those they consider worthy of long-term survival."

Nevertheless, the appropriate role of the nephrologist when patients expressed a desire to stop dialysis was still hotly debated within the renal community. Some argued that a paternalistic approach was warranted when it came to matters of life and death. Emblematic of this mindset, Michael Kaye et al published a case series of patients who had asked to stop dialysis but had been convinced by their physicians to continue treatment.<sup>16</sup> Because all of the patients studied were ultimately grateful that they had been coaxed to stay on dialysis, the authors concluded that a paternalistic approach of this sort was "permissible in life-saving situations where patients' refusal is idiosyncratic and irrational." In a 1988 *Kidney International* expert case discussion, nephrologists and ethicists considered the case of a patient who had won legal authority to discontinue his dialysis treatments.<sup>17</sup> During the discussion, the patient's nephrologist, advocated for what would today be called a "person-centered" approach to discontinuation:

"In the final analysis, medical decisions are too important to be made solely by doctors. The decisions are too personal, too complex, and not merely scientific

decisions. Because of this, these decisions must be made with the patient and not for the patient. Our role remains both educator and student: we must give the patient technical advice and we must provide guidance based on our own experience, education and community and family influences. We must be willing to listen to their interpretations of what we say and modify our approach depending on their needs. If we perceive that our patients do not agree with our opinions, it is not our job to become angry and forceful and withdraw from caring for them. Rather, we should support the patients' decisions; it might be the only "right" decision for the individual patient. If after educating our patients about all possible options, we find that they still reach different conclusions than we would for ourselves, our job remains that of an advisor and friend."

However, there were substantial differences in opinion between panelists and not all agreed with this perspective. For example, another discussant offered:

"I would feel terrible having let a patient make an irreversible and fatal decision based on a temporary or transient problem and inspired by a poorly thought out series of actions...I wouldn't have any problem "pushing" such a patient. I would not bring him into the dialysis unit and strap him down, but I would push him as hard as I could and not feel bad about that."

Many of the same tensions continue to haunt contemporary clinical practice. In their 2007 account of interviews with dialysis patients and staff, Ann Russ et al described similar sentiments toward discontinuation among dialysis nurses. Their work also illuminated the complex dynamics at work when nurses pressured patients to continue dialysis, including affirming the patient's self-worth and making sure they did not feel abandoned. A nurse interviewed for their study explained:

"There's one patient. 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.'"

#### 4 | DIALYSIS DISCONTINUATION FROM THE 1990S ONWARD

During the 1990s, Lewis Cohen, Michael Germain et al at Baystate Medical Center in Massachusetts began to study the experience of dialysis withdrawal by talking with patients who had discontinued treatment and their bereaved family members. Their work—which included both systematic surveys to assess the quality of death from the perspective of bereaved family members and semistructured interviews with patients and family members—remains one of the only sources of information about patients' experiences and symptom burden at the end of life.<sup>18–20</sup> They found that, far from the "slow, agonizing death" Scribner had alluded to in his 1964 presidential address to the International Society of Artificial Internal Organs, death after withdrawal of dialysis was rated relatively favorably by most of the bereaved family members they spoke with. Some even viewed the option of stopping dialysis as a "blessing" because it offered a sense of control over the timing and circumstances of death.<sup>18</sup> Several studies during this period also revealed substantial variation in nephrologists' practices around dialysis withdrawal. Together, this work laid the



foundation for the 2000 Renal Physicians Association (RPA)-American Society of Nephrology (ASN) *Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*,<sup>21,22</sup> later updated by the RPA in 2010.<sup>23</sup>

As was the case in the 1960s and 1970s, decisions about dialysis discontinuation continue to be shaped by the same forces as dialysis initiation. However, today dialysis is far from the scarce resource that it was in earlier decades,<sup>24</sup> having instead become a powerful default treatment for advanced kidney disease, at least in the United States.<sup>25,26</sup> As Russ et al noted<sup>27</sup>:

“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.”

Available evidence suggests that in contemporary clinical practice, dialysis is typically framed as a life-saving procedure and the decision about whether to start treatment as a dichotomous choice between life or death.<sup>28–30</sup> Most commonly, dialysis is started at times of crisis when medical necessity tends to override patient choice. Under these circumstances, those patients who express a desire not to start treatment often face immense pressure to the contrary.<sup>28–30</sup> Thus, it is not surprising that some patients express regret about starting dialysis and/or are left feeling as if they had little or no choice in the matter.<sup>31</sup> As Russ et al go on to explain<sup>27</sup>:

“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.”

Dialysis discontinuation continues to be a relatively common occurrence among US dialysis patients. Data from the United States Renal Data System (USRDS) registry (based on information from the CMS death notification form) suggest that between 2010 and 2015, 23%–25% of patients discontinued dialysis before death, with higher rates in White and older patients.<sup>32</sup> For example, rates of discontinuation among non-Hispanic White decedents ranged from 28% to 31% over this time period, as compared with 15%–17% among non-Hispanic Black patients. Among patients aged 20–44 years old, rates of discontinuation ranged from 10% to 11%, as compared with 34%–38% among those aged 85 years or older.

However, a recent study from the Mayo Clinic suggests that USRDS data may substantially underestimate the frequency of dialysis discontinuation.<sup>33</sup> Among 1226 patients who received dialysis at the Mayo Clinic between 2001 and 2013, 536 died and 262 (49% of decedents) withdrew from dialysis before death. By reviewing the medical records of these patients, the authors were able provide a detailed characterization of the clinical context in which dialysis discontinuation occurs:

“A patient who is more likely to withdraw from HD is an elderly individual with multiple comorbidities who develops an acute medical complication with limited treatment options, leading to the decision to withdraw.”

This context is not so different to that described by Neu and Kjellstrand in the mid-1980s, raising the question of whether, and to what extent, the decision-making process around dialysis discontinuation has changed over time. As Russ et al astutely observed in their ethnographic work around dialysis discontinuation<sup>27</sup>:

“Like that of initiation, the process is characterized less by the exercise of choices than the imposition of health exigencies that demand quick action.”

These authors went on to describe patients' substantial ambivalence around dialysis discontinuation, the complexity of how patients and staff negotiate and equivocate about the possibility of stopping dialysis treatments and the closely intertwined nature of decisions about dialysis initiation and discontinuation:

“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.”

Although many patients ultimately discontinue dialysis, few report ever having had a conversation with a health-care provider about prognosis and end-of-life care.<sup>31</sup> Although contemporary guidelines recommend that nephrologists engage in conversations about prognosis and treatment options with their patients, there is little evidence to guide practice in this area. Furthermore, these conversations can be extremely difficult and the skills and training needed to support this practice are generally not emphasized in nephrology training and continuing education programs.<sup>34</sup> It is, therefore, not surprising that most nephrologists do not feel prepared to engage in these kinds of conversations<sup>34,35</sup> and that many dialysis patients lack a clear understanding of what to expect in the future.<sup>36</sup> Given the uncertainty around illness trajectories among patients with advanced kidney disease, nephrologists often delay discussions about prognosis until there is an acute event.<sup>37</sup> Furthermore, decisions about dialysis initiation and discontinuation are rarely included in the list of procedures covered in advance directives.<sup>38</sup> These factors likely contribute to substantial clinical inertia favoring continuation of dialysis with the result that—similar to initiation—decisions about dialysis discontinuation tend to be reactive and crisis driven and may not reflect the goals and values of individual patients.

## 5 | CONCLUSION

Despite the developments in palliative nephrology over the past 20 years, dialysis discontinuation remains a conundrum for patients, families, and professionals. Contemporary clinical practice guidelines support a person-centered approach toward stopping dialysis treatments and suggest that this should no longer have the negative moral connotations that it once did. However, little is still known about the impact of dialysis discontinuation on the experiences of patients and families and there is a paucity of high-



quality person-centered evidence to guide practice. To be able to support decision-making in this area, clinicians need better insights into how decisions to stop dialysis unfold in real-world clinic settings and the symptom burden, emotional and existential concerns, and other palliative outcomes that patients might expect when they discontinue treatment.

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