

## case study

# Dirty Blood

**M**y blood is dirty,” Brian explains to the triage nurse when he arrives at the emergency room requesting urgent dialysis. He has a dialysis catheter in place and says his last dialysis was approximately one month ago. Further questioning reveals that he has autosomal dominant polycystic kidney disease (PCKD), which also afflicted his father, an uncle, and two cousins. His father died of kidney failure when Brian was a teenager.

Brian is now in his forties and has worked a series of construction jobs—some with health insurance, some without. Six years ago a doctor discovered his elevated blood creatinine level. He saw a half dozen nephrologists before beginning dialysis, but never the same doctor twice, and when asked he cannot recall any of their names. A year ago, his creatinine level reached fifteen (normal is about one) and doctors discovered

fluid around his heart. This was when he started dialysis.

Brian says that since then, he has had no problem maintaining fluid balance or safe potassium levels, and he has continued to make urine. Yet he thinks he’ll be dead in five years no matter what he does because every other family member with PCKD has died within five years of kidney failure. Because he wants to hike, be with friends, and travel “in the time I have left,” he had asked his nephrologists if he could come for dialysis once a week. His doctors didn’t agree with this plan, believing he could live for decades with adequate dialysis or a kidney transplant. They pointed out that the survival rate for patients with kidney failure has improved since his family members became sick.

Brian wasn’t convinced, though, so he had looked into this claim online. According to the U.S. Renal Data Sys-

tem, the survival prognosis for a patient of his age and diagnosis is eight to ten years—certainly longer than his relatives, but hardly the “decades” his doctors claimed. He also refused the suggested transplant because his uncle had one and then died of cancer. His doctors denied a connection, but Brian also found medical studies on the Internet that contradicted them.

Brian had begun skipping dialysis. Finally, the dialysis social worker called his mother to ask her to persuade her son to come more regularly. Angry at this violation of his privacy, Brian stopped going altogether. When he tried to find another dialysis center, he was told he had to be referred by the first center. As a result, he now receives no regular dialysis. About once a month, he feels ill and visits the emergency room.

Emergency room medical staff arrange for Brian to receive immediate dialysis, but during it, he develops chest pain and low blood pressure. Although doctors advise him that he may be suffering a heart attack, he says he’s heard that before and refuses further evaluation or hospital admission. The next morning, he is found dead in his home.

Did Brian’s providers mishandle his case? Could the details have been handled differently?

## commentary

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**B**rian knew that dialysis once a month wasn’t enough, but unlike his doctors, he wasn’t convinced he needed dialysis three times a week. He valued his independence and control over his time, in part because he underestimated his survival. Conversely, his physicians overestimated his prognosis,

which colored their perceptions of the burdens and benefits of more frequent dialysis. Unfortunately, Brian’s skepticism and even outright distrust were reinforced by what he viewed as misinformation (or may even have viewed as deception). Mistrust undermined any progress toward shared decision-making—the ideal promoted both by practice guidelines and by evidence that new dialysis patients who report greater participation in decision-making have improved outcomes five years later.

The Renal Physicians Association and the American Society of Nephrology Clinical Practice Guideline on Shared Decisionmaking specifies that “the primary care physician or nephrologists should hold a discussion with the patient or legal agent about life expectancy and quality of life.” Some nephrologists have expressed concern about this, however, arguing that survival figures will frighten patients and that available survival statistics are based on older treatment protocols started years or decades ago. Because treat-

ments have improved, patients starting dialysis today will probably survive longer than those who began dialysis a decade or more ago. Brian's conviction that he had five years to live based on family members' experience could have been explicitly addressed if, along with survival outcomes based on older treatments and data, his physicians had presented estimates of more favorable future survival based on less certain data, thus combining hope and realism. Painting too rosy a picture for Brian and skeptical patients like him can backfire. Particularly for genetic diseases such as PCKD, patients come to the medical encounter with some experience and information. They need to know both that treatments may have changed since parents or grandparents became sick, and that genetic diseases do not always manifest at the same age or with the same severity in all members of a single family.

Brian's intermittent insurance coverage contributed to fragmented care long before his kidneys began to fail. He could not name any of the nephrologists who had participated in his care. Lack of continuity reduced the chance that Brian and a physician would develop a trusting relationship and lessened the possibility for open communication about treatment goals and means of achieving them. Trust in his providers—already undermined when an earlier doctor dismissed the risk of cancer from renal transplant—had little chance to develop without consistent contact with a single physician over time, and his tenuous relationship with the dialysis center dissolved when they betrayed his trust by violating his confidentiality.

Brian's withdrawal in the face of conflict with providers—sometimes perceived as an individual's pathology—may actually illustrate a strategy used by working class, minority, and other patients who feel disempowered, ignored,

frustrated, or abused. Noncompliance represents at times a wresting of power from doctors. Unfortunately, patients who take control this way often find it difficult, as Brian did, to reestablish care because of waiting lists, referral requirements, transportation problems, or inability to find a willing provider. The second dialysis center's requirement for a referral (from providers he distrusted) illustrates another system factor that contributed to Brian's decision to use the emergency room to meet his dialysis needs.

Although Brian's nephrologists could have accommodated his request for weekly dialysis, they may have considered this course of action too risky. But negotiating a different one would have required detailed conversations about prognosis, treatment, and goals of care in an atmosphere of trust, with all parties confident that Brian understood the magnitude of the trade-off he was making.