Planning for a Kidney Transplant
Is My Doctor Listening?

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This article grew out of the personal experiences of the lead author. The article uses the first-person singular to communicate about those experiences, but the work reported here was a joint effort.—Ed.

In the spring of 1992, 5 years after learning that I had polycystic kidney disease, I met with the transplant team at the University of Minnesota to discuss my illness and future treatment options. I was 46 years old. At 25% to 30% of normal, my renal function was still more than adequate to sustain life (serum creatinine level, 256.4 µmol/L [2.9 mg/dL]), but I wanted to make plans well in advance of reaching end-stage renal failure.

When I explained to my wife, Catherine, that a kidney could be transplanted from a living donor who was not a blood relative, she volunteered to be tested. We soon learned that we were compatible in a way that went beyond our shared fondness for Mideastern food and Midwestern folksiness. Knowing that we could share vital organs, we decided not to wait until the last possible moment to act, but would time the transplant based on quality-of-life issues. I was the best judge of how I felt and since Catherine was agreeable to an early transplant, the timing decision should ultimately be up to me.

Over the next year my symptoms worsened, and by early 1993 Catherine and I realized that I had crossed the boundary. I no longer had the energy to enjoy anything. It was time for the transplant.

My doctors were aghast! How could I consider a transplant at this stage of my illness? At 15% to 20% of normal (serum creatinine level, 380.1 µmol/L [4.3 mg/dL]), my renal function was still well above the standard dialysis threshold of about 10%. What was my problem?

While they had agreed that Catherine and I should make the decision, they apparently had not expected us to deviate substantially from standard practice. Perhaps we would choose to act a few months earlier than usual, but certainly not a year or more before I had reached the 10% mark. They tried earnestly to dissuade me, explaining that my illness might progress more slowly than anticipated and that I should not risk complications or graft failure sooner than necessary.

The transplant team abided by our wishes, but they continued to protest until the very day of the operation. Their uneasiness caused me great anxiety. What if they were right? Was I being irrational?

Having been trained in the decision sciences, I tried to assuage my anxiety by doing what I knew best. I built a decision tree. Shortly before the transplant I sketched out a decision analysis that suggested that my desire for early transplantation was not irrational in view of the potential gain relative to the risk. Unfortunately, I was too debilitated at the time to undertake a full analysis and felt that I could not share the crude preliminary effort with my doctors.

It seemed clear to me that I enjoyed a candid, trusting relationship with my physicians. Why, then, were they so surprised and perplexed by my request? To address that question, I will first summarize the full analysis that I completed after my recuperation, then reflect on how divergent perspectives can impede communication between patients and physicians and how formal decision tools might facilitate shared decision making.

A decision analysis formalizes the notion that a person will risk something bad for the chance to enjoy something good when there is a favorable balance between risk and benefit. Decision analysts use numerical indicators to quantify potential gains and losses, then perform calculations to determine whether the likelihood times the attractiveness of the potential gain more than offsets the likelihood times the unattractiveness of the potential loss. If so, according to decision theory, the risk is worth taking. Technical details2,9 and

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scholarly debates about decision analysis can be found elsewhere.

The Timing Decision
In early 1993 I faced this choice: act now or wait? A rational decision would consider graft survival statistics, complication and death rates associated with transplantation and long-term immunosuppression, my quality of life at the time, the quality of life I could expect with a well-functioning renal graft, and that which I could expect if I required dialysis due to graft failure. Since a palliative bilateral nephrectomy was to be performed in conjunction with the transplant, the estimated likelihood of pain relief and risks associated with nephrectomy also had to be considered.

Tree Structure
Had I decided to delay transplantation, I would have waited for my condition to worsen, then reconsidered. The decision tree (Figure 1) displays this sequence of choices in 5% increments of renal function, beginning with the decision node on the left (square symbol). Each increment corresponds to an anticipated 12-month waiting period. At that rate, I could have delayed treatment for a maximum of about 2 years, since renal replacement therapy would have become mandatory when my kidney function fell below 10%.

A scenario refers to a sequence of events along a path leading to a terminal node (triangle). Analyzing a decision tree requires calculating the probability and relative attractiveness (or unattractiveness) of each scenario. Node C in Figure 1 identifies a scenario that includes the decision to operate immediately, the occurrence of a nonfatal complication, the resolution of abdominal pain, and a successful graft. Each branch labeled "graft fails" actually subsumes numerous graft-failure scenarios corresponding to varying lengths of graft survival up to the time horizon of 10 years.

Computational Method
The probability of a scenario is calculated by combining probabilities associated with each chance event. For scenario C, combining an estimated 60% chance of significant nonfatal complications, an estimated 50% chance of pain relief, and a 65% graft survival rate at 10 years yields \((0.60) \times (0.50) \times (0.65) = 0.195\), using a 10-year planning horizon.

The attractiveness of a scenario is determined by asking the patient to assign a quality-of-life rating, or "utility," to that scenario. A scenario may consist of several stages, each characterized by a different quality of life—for example, a scenario that includes several years of good health after transplantation, followed by graft failure and subsequent dialysis. The aggregate utility of such a scenario is calculated by adding together the patient’s utility during each stage weighted by the amount of time spent in that stage. The aggregate utility may be referred to as the number of "quality-adjusted life years."

Finally, to determine the optimal decision, one multiplies the probability times the utility of each scenario in the upper ("operate") branch, adds these together, then compares that sum with a similar computation in the lower ("wait") branch.

Utilities
I used a modified “time trade-off” procedure to assign utilities. In the conventional time trade-off, the rater decides how many years of life he or she would be willing to trade in exchange for improved health during the remaining years. The more years the rater would trade, the lower the utility of the status quo. I substituted hours for years because I found it easier to contemplate the number of hours I would sacrifice each day for the rest of my life than the number of years I would give up in a lump sum at the end.

Starting with a base of 16 waking hours per day, I assigned utilities to each of 2 health states by deciding how many hours I would give up in return for full health during the remaining hours. “Full health” meant a well-functioning kidney and freedom from abdominal pain and adverse effects of immunosuppression. To grasp the meaning of giving up an hour, I imagined how my life would be affected if the clock jumped ahead an hour every evening—daylight saving time restarted every 24 hours! I decided that given my quality of life in early 1993, I would have sacrificed 2 hours daily to achieve full health for the remaining 14. My utility rating was therefore \(14/16 = 0.875\).

The same process yielded 0.844 for life with dialysis (or with 10% kidney func-
tion, the approximate physiologic equivalent of dialysis). By definition, a utility of 1.0 corresponded to 100% kidney function. Fitting a smooth curve through these 3 points produced the lower graph of Figure 2. Interpolation yielded 0.857 for 15% kidney function. This curve incorporates the effects of abdominal pain superimposed on the effects of progressive uremia. I felt that these problems each detracted about equal amounts from my quality of life. If I had not had painful symptoms, higher utilities would have produced the upper curve in Figure 2.

I designated zero utility for the immediate posttransplant period and a rapidly increasing utility during recuperation, assuming no serious complications. A penalty equivalent to 30 days at zero utility was used for scenarios with complications.

Results
The analysis yielded 8.79 expected quality-adjusted life years for operating vs 8.77 for waiting. How, one might ask, could a person base an important decision on such a small difference? In fact, the small size of the difference makes sense. The decision tree describes the choice I faced when I had just “crossed the boundary” between feeling that I should continue to wait and feeling that I should act. Rather than providing a clear solution, the analysis suggests that either alternative would have been rational—precisely what my intuition had been telling me and what I had been telling my doctors. Had I not been bothered by abdominal pain—that is, had my utility function resembled the upper curve—the analysis would have favored waiting until I reached 10%.

My doctors discouraged early transplantation, in part because they could not accurately predict the future progression of my disease and worried about possible consequences of forfeiting my native kidneys prematurely. I therefore needed to test a range of assumptions about the future course of my disease and observe the effect on the output of the model—a process known as sensitivity analysis. Repeating the analysis with successively more optimistic scenarios led to a startling result: the preference for immediate operation persisted for every scenario including the extreme case in which I never reached end-stage renal failure! This observation led to the discovery of a mathematical theorem that explained this apparently bizarre result as a consequence of the inherently monotonic behavior of a graft survival curve. The theorem states that once a patient with progressive organ failure reaches the point when the patient—extrapolating his or her historical pattern of disease progression toward the future—prefers transplantation over further delay, the anticipated rate of progression is immaterial. The patient’s preference turns out to depend entirely on the current burden of disease.

A CASE OF CROSSED SIGNALS

Given that I had maintained an ongoing dialogue with my physicians, why did they balk when Catherine and I announced that we were ready to act? How could we have talked so openly, yet communicated so poorly? The answer, I believe, is that different patterns of thinking can interfere with patient-physician communication, causing misunderstandings even when the parties have a trusting relationship. In my case, interference seems to have crossed the signals.

Divergent Frames of Reference

Physicians and patients have divergent frames of reference. When the physician is thinking about the serum creatinine level, the patient is thinking about his tennis game. In principle, physicians may acknowledge the importance of quality-of-life issues, but in practice they often dismiss patients’ subjective reports as too “unreliable” to serve as the basis for major therapeutic decisions. When “I have been feeling terrible” is met with “. . . but your numbers look fine,” signals have become crossed. Divergent frames of reference make it difficult for physicians to hear what patients are saying.

Crude Measurements

A physician would never record a blood pressure as “elevated,” but physicians sometimes make equally crude measurements when eliciting subjective data. This probably happens because physicians do not think of the elicitation of subjective data as a “measurement” at all. “How have you been feeling?” produces data as precise as “blood pressure elevated.” If the question is reworded, “On a scale of 1 to 10, how have you felt over the past week?” useful data begin to emerge. For one thing, the question in this form does not sound like a social courtesy. It sounds like a serious inquiry. For another thing, the physician can repeat the question at each visit, compare the response with previous measurements, plot the data over time. This apparently minor change would enhance communication and improve the medical record.

Failure to maintain careful historical records of subjective data can obscure insidious changes. Symptoms may evolve slowly, but the cumulative effect can be profound. If differences from visit to visit are small, the physician may not realize that anything has happened.

UNCROSSING THE SIGNALS

Life is a subjective, unpredictable experience. Patients and caregivers must...
therefore communicate about subjective, probabilistic data. For physicians to know how an illness affects a patient, they must treat subjective data with the same respect they give physical findings and laboratory measurements. They must, for example, become accustomed to eliciting a scaled response to How-Have-You-Been-Feeling. When HHYBF begins to appear alongside HEENT on a progress note, that will, indeed, be a sign of progress!

One does not need a cardiac monitor to detect a heartbeat. Just as physicians know when to use a stethoscope rather than an oscilloscope, they need to know when to use a scaled How-Have-You-Been-Feeling question rather than a ping-pong searching, time trade-off utility assessment. Simple tools can be elegantly efficient, taking no more time than the cruder methods they replace—ear-to-cist auscultation or pititely vague interrogation. Oscilloscopes and time trade-offs provide added precision when the physician needs a closer look into the heart.

When a patient asks, “Doctor, what would you do in my shoes?” the well-intentioned physician tries to answer honestly, but the answer will not help the patient unless the two happen to have similar outlooks. When I decided to have an early transplant, I had reached a point in my life when I felt like being selfish. I just wanted to feel well and was willing to risk life-threatening complications before it became medically mandatory to do so. I felt that, since my children were grown, I could afford to be selfish. My doctors might have felt differently in “my shoes.” I, myself, might have felt differently at another time.

Incorporating subjective data into medical decision making will require a paradigm shift. When my physicians cheerfully allowed that I should make the decision, they may not have fully appreciated their radical concession of authority. Not until a year later when I went to exercise that authority did the ramifications of their largesse strike home. Such a fundamental change in the traditional model of decision making in medicine will not come easily.

Although decision analysis can improve communication, it has notable limitations: inconsistencies among utility elicitation procedures, burdensome data requirements, and a less-than-solid theoretical foundation. While it is important to acknowledge these limitations, imperfect tools are probably better than no tools at all. By inducing physicians and patients to work together, formal methods like decision analysis promote a richer dialogue and a fuller understanding of the issues. These are rewards worth pursuing. Perhaps doctors should take a closer look at tools to enhance their listening. At least one patient is ready to do some talking.

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REFERENCES