

J.R.'s Choices

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Our patients often make choices about their health care. Sometimes they decide between two medications that differ only in cost. Other times, they may decide whether to pursue a given treatment based on their willingness to accept the risks of the treatment and its chances for improving their quality or quantity of life. We try to help with these decisions by providing what information and guidance we can. These are decisions of cost, benefits, risks of disability, and hopes for recovery. They are sometimes difficult choices, to be sure. However, our patients must also make other choices, choices that balance their health with the well-being of loved ones, choices that we can scarcely help with. J.R.'s story is one of difficult choices.

I met J.R. about 3 years ago. He presented to the office as a new patient at 62 years of age with the acute problem of shortness of breath and pedal edema for 1 month. He had no significant past history except a 20-pack-a-year smoking history. He had not been to see a physician for approximately 5 years and had retired 3 months ago after 35 years in the custodial department of a major corporation.

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His physical exam revealed marked pedal and leg edema, diffuse crackles, and a grade 4/6 heart murmur. Echocardiography obtained the day after his office visit revealed severe mitral valve regurgitation.

At the time of his initial visit and echocardiogram, it was clear that he needed to see a cardiothoracic surgeon to consider mitral valve replacement surgery. This surgery provided the potential for both improved quality and quantity of life, two of the major goals of health care. In practice, achieving this potential proved to be a problem, since J.R.'s care rapidly became more about finances and the economics of health care than about medical decision making.

While employed, J.R. had health insurance through his employer. Insurance coverage was, however, not a part of his retirement plan, and he had recently let his continuation of benefits lapse due to expense. He had never had a large income but owned his house and another smaller house where he had lived previously. He had a small amount of money in a corporate 401K plan. He lived with his wife, who was 4 years younger than him and in good health. In short, he had a few assets, enough as long as he and his wife stayed healthy and enough to pay for routine office visits and tests.

Unfortunately for J.R., routine office visits and medications were not the solution to his cardiac problem. He was ineligible for Medicare, caught between early retirement and a disability benefit

that arrived too late. He did not qualify for Medicaid or institutional charity care because his financial assets, though limited, exceeded eligibility thresholds. He was unwilling to "spend down" his assets to become eligible for charity care or Medicaid because he equated his assets very strongly with his wife's future well-being. In short, he and I both knew that surgery would help his condition, but he could not find a way to go forward with the surgery—he just would not put his wife's future at risk.

Though his swelling decreased slightly with diuretic therapy, the improvement was temporary. His poor prognosis without surgery was borne out over the following 12 months by progressive debilitation, new-onset atrial fibrillation with a rapid ventricular response, and intractable dyspnea. During this time, his primary caregiver was one of our third-year residents. J.R.'s prognosis and possible treatment options were discussed with J.R. and his wife again and again. He had several conversations with a social worker knowledgeable about his options for charity care and Medicaid. He steadfastly refused to proceed with further treatment as long as he did not feel too sick and his assets were at risk. He still preferred to wait until he was old enough to begin receiving Medicare benefits.

Two years after the initial diagnosis of mitral valve regurgitation, he presented to the office with tachycardia, marked dyspnea, oxy-

gen saturation levels in the 80s, and profound edema. At that point, he was scared. He stated that he was ready to seek further care in spite of the financial consequences and was hospitalized. After arriving in the hospital, but before being seen by cardiologists or cardiothoracic surgeons, his heart went into an unstable rhythm and he died. He was 2 months short of 65 at the time of his death.

J.R.'s story and his choices are similar to many in his position. His first choice was made before he even came in to the office—he opted not to pay to continue his health insurance coverage until becoming eligible for Medicare at age 65. Some may view this as simply a mistake. Certainly, in hindsight, it appears so. He was clearly taking a risk. However, he was in some ways acting to decrease the cost of his health care. He hadn't needed care for 5 years and could afford routine doctor visits. The cost of continuing his benefits amounted to most of his monthly income. To him, his choice was sound. He didn't contemplate the need for a financially catastrophic procedure such as a mitral valve replacement nor did he have any idea what such an intervention could cost.

His second choice, not to "spend down" his assets, seems an im-

possible dilemma. To choose the surgery and deplete his small retirement savings was to choose shame and loss of freedom for himself and uncertainty about his wife's future. This was balanced with the risk of death and consistently worsening quality of life with no surgery. J.R. agonized about this decision, as did we. This anguish had to have worsened his already poor quality of life.

Even if we assume that his first decision—to forego continuation of his health benefits—was a mistake, why should anyone be faced with such a decision? Do we want to have a health care insurance system that forces J.R., and others like him, to choose between his personal well-being and his wife's financial security—under any circumstances? He received a harsh punishment for his decision.

Much has been made of the idea of "moral hazard" in health care. This is usually seen as the hazard of people receiving care they may not need simply because they have health insurance. The idea of moral hazard is commonly used as an argument against universal health care coverage. In many instances, however, our system of providing subsidized health care only to the very poor, forcing patients to "spend down" their assets to qualify

for that health care, does little more than reverse the situation. Instead of people receiving care they may not need, in our current system people fail to receive care or services they clearly do need because they do not have health insurance and are unwilling to accept the risks—not only to their own health, which are substantial—but also to the health, financial security, and quality of life of loved ones in the future.

It is in cases such as J.R.'s that reliance on the idea of moral hazard to drive health care policy can force patients to make decisions that no one would want to make and, in my opinion, which no one should have to make. J.R. chose to conserve his small amount of funds to preserve his family's freedom and safeguard his wife's future at the cost of his own life. That he had to make this decision at all seems profoundly immoral.

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