Life and Death Choices as South Africans Ration Dialysis Care

Late last August, 41-year-old Amos Phillips arrived by ambulance at Tygerberg Academic Hospital near Cape Town, South Africa. His kidneys had failed. He was confused, struggling to breathe, and desperate enough to ask doctors to end his life.

The same month, a 43-year-old widow with three children was also treated at Tygerberg for kidney failure. The patient, Karen MacPherson, desperately wanted to live. She said she had been plagued by high blood pressure, a risk factor for kidney disease, since her children’s birth. “It's because of the high blood [pressure] the kidneys don't want to work anymore,” she said.

Dialysis Coverage on Facebook

Meet others who've dealt with dialysis on ProPublica's Dialysis Facebook page.

Kidney failure can come on suddenly and affect anyone. Some forms are partial or reversible. Others are permanent and fatal without treatment.

To live, both Amos Phillips and Karen MacPherson would need ongoing dialysis treatment to filter toxins from their blood, sustaining them until they received a kidney transplant. But needing treatment didn’t mean they would get it.

Public hospitals in South Africa strictly limit the number of expensive dialysis treatment slots for chronic kidney failure to save money for other pressing health priorities. It falls to the medical staff to do the rationing.

The situation in South Africa is strikingly similar to that of the United States in the 1960s, when dialysis first became available. Demand for the procedure was far greater than the supply, and hospital-based committees quietly rationed dialysis—much as they do in South Africa today.
In the United States, committees granted or denied dialysis in large part by judging how much a particular patient’s life was worth. A 1962 article in LIFE magazine exposed the selection process at one Seattle clinic, triggering public outcry. Lawmakers created a program that now entitles almost anyone diagnosed with kidney failure to dialysis treatment under Medicare.

A few kidney doctors have argued publicly that access in the United States has become too broad, including patients who are unlikely to benefit from the expensive therapy. They have called for limits on which types of patients should receive dialysis.

But where to draw the line? The scenes that unfold each week in Cape Town, South Africa, where committees meet to choose dialysis patients, are a reminder of how difficult any selection process can be.

I was granted access to closed dialysis selection committee meetings at the two hospitals that provide public dialysis services to adult kidney patients in the Cape Town Area. It is the first time a reporter has been allowed to attend a committee meeting at Tygerberg and report on the process.

An investigation by ProPublica recently highlighted the high cost of the massive, rapidly expanding kidney disease program in the United States and the poor outcomes experienced by many dialysis patients.

The challenge for the United States is to address systemic flaws and achieve the superior results that patients in other wealthy countries, such as Italy, enjoy. In less-affluent countries like South Africa, the central question is a different one: How can these nations expand access to dialysis—and in the interim bring some modicum of consistency and transparency to the heartbreaking task of rationing lifesaving care.

Global inequities

When it comes to expensive, chronic therapies like dialysis, there is still a stark divide between wealthy nations and much of the rest of the world. In the United States, Western Europe and Japan, there is widespread access to dialysis care, most of it paid for publicly. But in many countries, the vast majority of patients with kidney disease don’t have access to dialysis.
In South Africa, only the roughly one out of five patients who have a form of health insurance or the small proportion of patients who can afford pay are able to get dialysis at private clinics or hospitals based on medical need alone. The cost of paying out of pocket—about $20,000 per year—is nearly double the gross domestic product per capita.

The remaining patients rely on an overburdened public health system in which an increasing number of chronic kidney disease patients are denied dialysis.

“Probably in the middle of the last decade we were turning away 50 percent of the patients,” said Dr. Rafique Moosa, a kidney specialist at Tygerberg Hospital and head of the Department of Medicine at the University of Stellenbosch. According to him, as of August they were turning away 80 percent, and in November, only two out of 20 patients were accepted. “We just don’t have the resources to deal with the patients,” Moosa said. But deciding to reject patients for the program can feel like issuing a “death sentence,” he said.

“In a court of law, you have courts of appeal and you have a higher court and all those kinds of processes before the death sentence is eventually applied,” Moosa said. “Here, essentially if we say no, the process is essentially terminated.”

So, the doctors have adopted a firing-squad-like approach to share the responsibility and the burden. “It’s a tough process having to decide who lives and who doesn’t,” Moosa said. “One of the ways of dispersing the guilt and the blame and all the badgering that goes with this is to do it as a group rather than an individual.”

The question of how groups of medical professionals choose who lives is particularly important given South Africa’s history. Tygerberg was built during the apartheid era, when the government mandated racial segregation. The vast hospital has hallways that stretch out east and west, in wings that are mirror images. One side used to treat white patients. The other treated nonwhites.
For decades, a committee at the hospital has decided who gets dialysis treatment. In a recent study of historical data from Tygerberg’s program, Moosa found that patient selection often fell along racial lines. “What we clearly discovered in that initial paper was that black patients were disadvantaged,” he said.

The apartheid era ended with the first multiracial, democratic elections of 1994. However, between 1988 and 2003, Moosa’s study found, white patients were nearly four times more likely to be accepted for dialysis treatment than nonwhites at Tygerberg. (In recent years, the vast majority of white kidney disease patients have shifted to the growing private dialysis sector for care, and their cases are no longer subject to review by Tygerberg’s dialysis selection committee.) During that period, there was little in the way of detailed guidance governing the selection process. That left patients and the public with limited insight into the basis for the committee’s decisions.

Several years ago, the government announced cutbacks that would further squeeze the dialysis program. At the same time, the number of new kidney patients was skyrocketing thanks to a growing rate of diabetes and other risk factors.

Moosa protested the budget cuts and sought to have government officials in charge of his hospital take more public responsibility for rationing.

“We were making these clinical decisions that would have economic benefit to the hospital, and the hospital managers played absolutely no role in this,” he said. “We felt that was blatantly unfair.”

Provincial officials agreed to work with the medical professionals to establish official guidelines for patient selection—essentially a more standardized and explicit rationing system. Ethicists and several patients with kidney disease also provided input.

Participants differed somewhat over the criteria for allotting dialysis treatment—there are no universally accepted methods to ration health care. However, they worked to ensure that the selection guidelines were developed in a just way and that the selection process would be more accountable.
“The main thrust of this was to be fair and equitable and transparent,” Moosa said. The provincial government adopted the new system earlier this year. It calls for the dialysis selection committees at public hospitals to place patients into three prioritization categories based on a variety of medical and social factors.

This was the system that was in place when Amos Phillips and Karen MacPherson, two of the recent patients at Tygerberg, were considered.

The Committee

On a recent Tuesday morning, about a dozen medical professionals, stethoscopes dangling from their necks, gathered in a small conference room at the hospital. The committee meets weekly to decide who will be accepted into the dialysis treatment and transplant program.

The hospital’s longtime social worker for kidney patients, Marietjie Swart, presided. She projected a photo of Amos Phillips onto a large screen.

The image showed a man with closely cropped brown hair lying in his hospital bed.

Phillips’ doctor outlined his medical condition, and then Swart reviewed other aspects of his life that might have a bearing on the committee’s decision. She began with his age and where he lives. “He can read and write,” she added. “He speaks Afrikaans and Xhosa, as well.”

Phillips “never smoked, never used any drugs,” Swart continued. “He only drank over weekends with his wife, but they would only buy about four bottles, 750 ml, between the two of them.” Phillips was, Swart said, “not a party animal.”
That was a point in his favor. Under the guidelines, active substance abuse automatically excludes a patient from receiving dialysis.

Swart also discussed Phillips’ living conditions. “It’s a one-bedroom house, with a lounge, kitchen and a bathroom,” she said. The bathroom had a tub, sink and a toilet.

The guidelines call these “good home circumstances,” and they, too, improved Phillips’ chances of being chosen for dialysis. Running water, sanitation and electricity are important for performing a form of dialysis safely at home. However, these criteria can disadvantage the poorest South Africans, who often lack such utilities.

Swart offered more personal details. “He is employed on a farm,” she said. “His income is more or less 1,200-1,500 rand ($175-$220) a month.” He had “no criminal record” and was married to a 33-year-old woman. “They’ve got three children of 13, 9, and 4 years old, all three living with them.”

These factors—criminal and employment history, whether the patient is a parent—have little to do with the chances of benefiting medically from dialysis. They are, instead, measures of social worth.

Dr. Moosa said the committee used to weigh these factors heavily when considering patients for dialysis. “I suppose we used a utilitarian approach,” he said. “The question that we used to ask ourselves—you know, if we put this patient onto our program, of what benefit can he be to the society?”

According to the new guidelines, those factors are no longer considered. The ethicists who helped draw up the guidelines argued that medical practitioners should not judge which patients are the worthiest contributors to society.

Judgments are often wrong. For example, former prisoners might have been falsely convicted, especially during the apartheid years. Patients who lack their own children might be helping to raise others.
Most important, the ethicists said, are medical criteria. Is the patient healthy enough to undergo a kidney transplant? If so, he or she might someday no longer need dialysis, and that would free up a slot for a new patient.

The problem is, few actually are able to get transplants. There are far more good medical candidates than there are dialysis slots. Therefore, the committee falls back on subjective criteria—does the patient seem motivated? Does he or she have a good social support network?

The committee still discusses some social factors that are no longer included in the government-approved priority setting guidelines Moosa helped to develop for the province. For example, the checklist still used by the committee penalizes those who’ve been convicted of serious crimes and requires gainful employment for a patient to be accepted into “Category One,” the only category of patients guaranteed access to the dialysis program. Both of these “social worth” factors are missing from the new guidelines.

Moosa said in an interview that he had not had time to update the checklist tool to conform with the new guidelines, but that those factors are mentioned at committee meetings “more out of habit” and are “not something we pay a lot of attention to anymore.”

The assessment committee weighed the factors in Amos Phillips’ case, deciding whether he should be ranked “Category One” and guaranteed dialysis.

“I think he would almost be a Category One patient if it wasn’t for his late presentation,” Moosa said to his colleagues at the committee meeting.

By “late presentation,” Moosa meant that Phillips had arrived at the hospital after his kidneys had already failed. He needed to be put on life support, with a breathing tube and emergency dialysis, until he was stabilized. That bumped him to Category Two—not guaranteed a spot in the chronic dialysis program.

The case for Karen MacPherson
The same day, the committee members also talked about Karen MacPherson, the widowed mother of three.

Her picture was projected on the screen. Her wide eyes peered at the camera through large plastic glasses. Dr. Yazid Chothia described her medical and social situation.

“She’s the only breadwinner,” he said, and she had been raising several children. Now other family members were caring for her. “Yesterday they brought her in here because she was nauseous, vomiting,” Chothia said. “It sounds like the family is struggling in terms of taking care of her.”

MacPherson’s case had come to the committee before. She had many characteristics that counted in her favor.

She was well below age 60, the cutoff for initiating dialysis under the government-approved guidelines used at the hospital. She didn’t have any other serious medical or psychiatric disorder, which could disqualify her. She had a home near the hospital with running water and electricity.

Before the new guidelines were adopted, the selection committee might have given great consideration to the fact that she was a mother with a steady job and no criminal history. But the committee had recently turned her down.

“We didn’t accept her for the program?” Moosa asked his colleagues. He had been on vacation when the case had come up before.

“It was mainly based on her BMI, prof,” Chothia said. “Her BMI was 39.”
BMI is body mass index. MacPherson’s was high. She was obese.

Although obese patients do better than average on dialysis, they have a poorer prognosis when it comes to a kidney transplant. That, according to the new rationing guidelines, takes precedence.

Moosa accepted the committee’s previous decision. MacPherson had been assigned to Category Three—automatically excluded from dialysis treatment. She was already very sick.

“It probably won’t be for very much longer,” Moosa said. “Shame.”

The committee members took some steps to help her. They agreed to provide a letter that could be used to relieve a debt. They also referred her to Eagle’s Rest, an inpatient hospice located on the grounds of an evangelical church.

Grasping for hope

The next day, MacPherson lay in bed at the hospice beneath a pink blanket. She trembled when she sat up. She was too nauseated to keep down her food.

Her father came to visit, and she asked him about her prognosis. “Did the doctor tell you how much longer I’ve got to live?”

“You’re going to live long enough,” her father, Richard MacPherson, answered. “Don’t you worry about that. You just get well. That’s all.” He smiled at her. “There’s no limitation. The doctor can’t say that.”

With her family’s support and the nurses’ prayers, Karen MacPherson tried to stay hopeful.

“I want to get better, I want to get out of here, get my life back on track—get back to my kids,” she said. “My daughter needs me.”
As she spoke, she seemed unaware that she had been turned down for dialysis, or even that dialysis could help her. Her doctor later confirmed that he didn’t tell Karen MacPherson about the program, although he said he informed her father.

According to the prioritization guidelines, patients or their family members are supposed to be fully informed of the committee’s decision and the reasons for denial and given the opportunity to appeal.

“It’s an ethical obligation to actually communicate openly, truthfully, and sincerely with one’s patients,” said Dr. Keymanthrie Moodley, a bioethics professor at Tygerberg and Stellenbosch University. Moodley said this can prevent the misconception that a patient was rejected for reasons of race or socioeconomic status. “To create a healthier society from both a physical and a mental and psychological perspective, an open line of communication is absolutely critical.”

Dr. Moosa said the guidelines require informing patients or their family members however challenging that may be.

“The reality is that it’s very difficult to go to a patient and inform them, well look, there is this particular form of therapy which is available to you which will help you live another reasonably healthy life for another five to 10 years, and then in the same breath say, well, unfortunately I can’t offer it to you,” he said. “I think it’s actually cruel to dangle that almost as a carrot in front of the patient.”

Pushing the boundaries

South African physicians are looking to expand public dialysis programs by partnering with private clinics, campaigning for more funding and trying to cut costs. Still, any such plans will come too late for today’s kidney patients. Tygerberg Hospital has no free slots for dialysis.

Sometimes, however, room is made for exceptions.
Several months ago, one of the patients who had received a kidney transplant at Tygerberg in the mid-1990s experienced rejection of her organ and developed kidney failure again. She was brought before the committee to be reconsidered for dialysis. She was now 59 years old and experiencing heart failure—no longer a candidate for kidney transplant under the guidelines, and therefore no longer a candidate for dialysis at the public hospital.

“If you look at the criteria, she should not be [accepted to] our program,” Swart said. But the woman had provided many years of service to the hospital’s patient-support group overseen by Swart. By this point, the woman had secured private health coverage, known as “medical aid,” but she wanted to continue being treated at Tygerberg, which no longer accepts such patients.

“I just said, ‘Guys, there’s no way that you’re going to turn down this lady,’” Swart recalled. “‘She’s my left and my right hand.’” The committee approved her, and she currently performs dialysis at home that is overseen by the clinic at Tygerberg. “She’s just a very, very special case,” Swart said.

She is not the only one for whom extraordinary efforts have been made.

The day after the recent committee meeting, Dr. André Nortje went to the bedside of kidney patient Amos Phillips. “Mr. Phillips, we discussed you yesterday in our meeting,” Nortje informed him.

The committee had classified Phillips as a Category Two patient—eligible for dialysis only “provided resources allow.”

The program was full, but Phillips was borderline. The committee members thought he had a good chance of benefitting from dialysis, and they hate turning anyone away. They had accepted him for dialysis.

“We decided at our meeting yesterday morning that we will support you in terms of that,” Nortje said. “What I mean by that is that we will offer you, in future, a kidney transplant.”

Phillips looked up at the doctor from his hospital bed. “Yes. I understand.”
“You understand?” Nortje asked.

“I understand and am very happy.”

Phillips began receiving regular dialysis and soon returned home to his family.

Karen MacPherson was buried two weeks after the committee meeting—on what would have been her 44th birthday.