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# Putting a Face on Poverty — A Tale of Two Counties

by Sharon Lee

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*Disparities in social and economic status create a wall between the well and well-off and those living on the other side of town: the poor, the chronically ill, and the dying. In some cases, the needy to whom we turn a blind eye, those who need healthcare the most, live next door to us or across the street, only a zipcode away. The case studies presented in this article draw attention to these members of our community and the imperfections in our present system.*

Our system does not provide rational healthcare. The limitations may be most evident for those with chronic disease, and those who are dying.

In earlier times those who were well and well-off provided for others in the village who could not care for themselves. The able saw the disabled daily in the village commons and could not forget their needs.

Not so, in our time. Given, among other things, the vagaries of our economy, job transience, and the break up of extended families, the neighborly village no longer exists. Today we have vast ghettos where the poor congregate in low-income housing without jobs or transportation or other ways to escape bleak economic realities. Those who are better off live miles away with real and figurative walls even between near neighbors. Today we do not regularly see the faces of the needy; they are easily forgotten. The poor die in part because they are not remembered.

Remembering is important. Remember, for example, that bare statistics are determined by counting individuals — individuals with names,

faces, and unique stories. Consider the stories hidden behind the U.S. Census Bureau's collection of county demographics. Wyandotte, a county in Kansas, contains many neighborhoods in which the poor live in isolation from the affluence experienced in nearby Johnson County. Or use an even smaller measure. Table 1 compares the levels of education, employment, and income attained per capita in three Wyandotte county zipcodes to the levels of attainment in one of the least affluent zipcodes in Johnson county.

We know that poverty leads to poor healthcare and higher death rates. The age-specific death rate for Wyandotte County is twice that of Johnson County. Near the Family Health Care Clinic where I work more than 40 percent of households have no car — in a city where buses traverse even the busiest streets only a handful of times in the early morning and late afternoon. Even in affluent times, as many as 15 percent of these residents are unemployed and half the adults did not complete high school. Many are immigrants who have language and cultural barriers that exacerbate their poverty.

**Table 1 — Social and economic indicators in three Wyandotte and one Johnson County**

Zipcodes	Education		Jobs	Income	
	High school grad	College grad	Unemployed	< 200% poverty	Per capita income
Wyandotte County					
66101	51.86	6.08	14.78	64.58	7,449
66103	73.76	21.22	7.43	47.78	10,651
66105	49.08	1.70	10.09	5.17	8,146
Johnson County					
66209	98.66	63.04	1.53	2.44	36,127

What do these numbers, the statistics of many inner city or rural areas where the poor gather, mean?

### In Juanita's Case

Think about what they mean to Juanita. She is forty-two, a U.S. resident with a work permit who has worked as a housekeeper for five years with no benefits. How would you feel if you were Juanita?

You just get by. Providing for yourself and your eight-year-old daughter is tough at times on an \$8.00 hourly wage. You work forty hours a week, but your income is below the poverty level for a family of two, and you do not qualify for state medical assistance, which is set to kick in for working families at about one-third of the poverty level. You have not heard from your husband in more than six years. You have diabetes, but only occasionally have checkups at the free screenings near your work. The medication they told you to buy costs \$62 per month so you have never filled the prescription.

One morning as you wake and stretch, you feel a lump in your right breast. You haven't noticed it before. You tell yourself at first it's just a bump from running into the washing machine door at work. It doesn't really hurt. You remember that your grandmother died ten years ago in Guatemala from a cancer on her chest. You worry a little, but get up, fix breakfast for your daughter, and get ready for work.

Two months later the lump is still there, you have felt it for weeks now, but it seems like it may be smaller. You don't speak English well, and most of the other women at work are Laotian. You worry alone.

Six months go by. You are certain that the lump is larger and you are becoming scared. You have no phone, no car, and yet you decide you need to see a doctor. There is a clinic that allows you to spread your payment over time and even reduces the charges for a visit. You walk to the clinic after work and learn that the doctor believes you have breast cancer.

Then the doctor explains that you need a mammogram. It will cost one-fourth the money you and your daughter live on for a month. At first you decide to avoid the X-ray cost. But, three weeks later, the doctor calls you at work and learns that you have not had the X-ray. You are embarrassed but you explain that you cannot afford this test.

To get the mammogram for you — and after determining that you cannot qualify for state assistance until after a diagnosis is made — the doctor calls a church for a donation. When she tells you about it, you are embarrassed, but you accept the help.

Two weeks later, the mammogram is read as positive, the doctor tries to get you an appointment with a surgeon. She tells you that the surgeon has agreed to see you in two weeks

without an up-front charge, but when you take off from work and get to the surgeon's office, his receptionist tells you that you must give her \$65 before you can be seen. You leave the surgeon's office, looking down to hide your shame, and walk back to the clinic. Again the clinic doctor calls the surgeon, and he agrees to see you in another week.

The doctor agrees that you have cancer and orders a biopsy. He suggests that you get state assistance and schedules the biopsy two weeks later. You have to cancel the biopsy because the state social workers tell you to come to their office in three weeks. You take off work again, reluctantly, but here you learn that the state will not help you because you have not had the biopsy to prove the diagnosis.

You go back to the clinic and the doctor talks to the surgeon. Both agree that the surgeon and the hospital will be paid by the state "retroactively" after the diagnosis is made. The surgeon agrees to perform the biopsy and postpone billing for the work. Then the clinic doctor finds a hospital that will allow the biopsy surgery to be done and the billing postponed.

The biopsy is finally completed. More than three months after the doctor has told you the lump is cancer, it is proven to be breast cancer. You have to undergo more surgery and radiation and the cancer specialist gives you a prescription

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for Tamoxifen, a medicine to prevent the cancer's recurrence. Tamoxifen costs about \$100 monthly. During this time all treatment is covered by the state assistance program that started when you were off work and had the proven diagnosis of breast cancer.

Depending on where you live state assistance may vary in what medicines, or treatments are covered. Copays, limitations on formularies, limitations on the number of pharmacies, or caps on the cost of prescriptions may be difficult to follow. Eleven states limit prescriptions by number and other states limit them by capping costs. If you live in Arkansas you will be limited to three prescriptions monthly. Depending on the number of prescriptions needed, the Tamoxifen may not be covered. In Kansas it was. In fact, the diabetes medication that was prescribed is also covered.

However, the state assistance comes to an end when you return to work a few weeks after the surgery and radiation treatment. You learn that the Tamoxifen costs more than \$100 a month. Your pay check is only \$250 a week. It is too expensive. You begin by stretching the medicine, thinking that by taking smaller amounts, or taking it once daily, or every other day, it may still help you.

As more pressing problems emerge, the money you have set aside for medicine is spent. Your daughter needs a dress for the school Christmas pageant and she has outgrown her last year's winter coat. Weeks go by without the Tamoxifen, then months, until one day you wake up, stretch, and notice a lump in your left breast.

This tragic story is about a real patient at a real clinic in Wyandotte County, Kansas. Juanita (not her real name) is now battling recurrent breast cancer and trying to survive long enough to raise her daughter.

If Juanita's case were a rare or unusual situation, it would still be sad. However, it is a tragedy that is repeated many times each day at the clinic on Southwest Boulevard in Kansas City, Kansas, and at similar clinics throughout the country.

Each day we make conscious and unconscious decisions to respond to the needs of the impoverished in our communities, or to ignore them. These patients are vulnerable for a variety of reasons: some because of poor choices; others because of poor circumstances. They literally die

for lack of medical care. When they disappear from our sight, their needs are not less burdensome, though we do not see them. Why do we not see them? They are still here, just on the other side of the wall.

### **Looking at Life on the Other Side**

#### ***Barbara's Story***

Barbara, a 32 year old woman living with her father, was brought to the clinic when her sister noticed a strange odor coming from Barbara's body. After much coaxing she allowed a physical which revealed a large external mass in the pelvic region. She did not allow a biopsy for several weeks. When it was finally completed the results came back positive for squamous cell carcinoma. Barbara refused further treatment despite numerous discussions with her family and physician. Though medical assistance and social services were available, Barbara did not accept them. In fact, 40 percent of people living in Wyandotte County are Medicaid eligible, but only 22 percent receive services.

Nearly eight months later, Barbara was taken to the Emergency Room by her sister, complaining of pain and constant incontinence of the stool. Once admitted, she underwent debulking and had a colostomy bag placed. The oncologist stated in the chart that the patient had "understood options for treatment and declined." The oncologist was unaware that the patient had cognitive deficits and tested out at the eight year-old level. After family discussions, the patient underwent palliative radiation therapy and accepted hospice aid with pain medications. She developed thrombi in her legs and was placed on Coumadin. She and her father were unable to keep up on their bills and were without water for several weeks before being evicted. Barbara lived some of her last few weeks in a homeless shelter.

#### ***Susan and Rolland — Against the Odds***

Susan has a hereditary urinary tract disorder with a horseshoe kidney, small urethra and bladder, and subsequent frequent infections. She has schizophrenia which is controlled when she is able

to buy her medications. Her husband, Rolland, has been a delivery driver at a company which provides no benefits to contract employees. They have no insurance. Rolland injured his shoulder helping a friend move in August. Since the injury, he has been unable to tote the deliveries and has cut back on his work.

In September, the pain in Rolland's shoulder forced him to seek medical attention. Initially he refused an X-ray due to the costs, but at a second visit two weeks later, he agreed to an X-ray "if it would help him get back to work quicker." The X-ray showed advanced lung cancer with metastases to his shoulder. Rolland applied for medical assistance and was denied because the family owned his truck and a car.

Rolland died in December. He had received some radiation and sold his truck to finance his medications. Susan got Medicaid the week after Rolland died.

#### ***Karen's Costly Medicine***

Karen was a bartender. She had no benefits. Her husband was disabled after a work accident which left him paralyzed on the right side. She had stomach pain that she thought was a little better when she took tums.

After four months of increasing pain, she could no longer stand it. She went to the clinic and was sent to the Emergency Room. She had pancreatic cancer which had metastacized to her liver. Although celiac plexus blocks are known to increase life-span and reduce the horrible pain of end-stage pancreatic cancer, she was not a candidate for the surgery because she had no means of paying for it. When she left the hospital, the morphine prescription she filled cost almost three hundred dollars. It lasted almost three weeks.

In your county, in your zipcode how would Barbara fare? Where would Rolland and Karen go for help? How much suffering must occur before Susan is eligible for help? ■