Found Down

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The title of my presentation today is borrowed from medical slang. "Found down" is a frequently documented reason why patients, particularly the elderly, are brought to hospital emergency departments. I will say more about this later, but want to begin and end by saying that our health care system, in particular our primary care, should also be "found down" by you today.

I appreciate the opportunity to come before you in order to address the urgent question: "Is poverty a death sentence?" As a rural general internist I can tell you that in my experience of the last fifteen years, in many instances, it is.

The World Health Organization* has shown in a recent extensive study that the underlying health of any population is primarily due to social determinants. Health status is generally predictable for individuals based on their level of education, income, occupation, geography and gender. Poverty is one of the most powerful predictors of poor health status and outcomes. Dr. Braveman's presentation today describes some of the biological mechanisms for this. I will share my clinical observations from my experience spent caring for poor and underserved populations in Franklin County, Massachusetts, where I founded a community health center in 1995.

While the poor literally start life with the cards stacked against their health and longevity, my life's work of creating access to care has convinced me that having access to medical care can mitigate, and lacking access can aggravate these predetermined disparities.

Our health center was started with a planning grant from the state Medicaid agency. At that time there were large numbers of patients in our community who were enrolled Medicaid recipients but they nonetheless had no access to actual care, because there were almost no local physicians accepting Medicaid insurance. This showed me early on that access to insurance and access to care were not the same thing.

Six months after opening the practice, we found that 75% of our patients were uninsured. Many were extremely sick. I remember a woman who came in complaining of rib pain. I only saw her once, as she died almost immediately of widespread lung cancer after

receiving the diagnosis from a simple chest x-ray that she had not previously been able to afford.

Another woman was brought in by her family over her increasingly feeble objections after she became nearly comatose. She had end stage liver disease and also died within weeks.

One of our first board members was a woman in her 50s who was very committed to the health center. She was also our patient, after years being uninsured and having no medical care. On her first routine exam in years there was a large, irregular abdominal mass. She died about a year later from colorectal cancer – a condition that we routinely screen for in primary care, and should detect in time to treat effectively in almost all cases.

An elderly man came to the health center with extremely disfiguring basal cell carcinoma of the face that had been present for over 20 years. Basal cell carcinoma is the most curable cancer of the skin, and the slowest growing. It never spreads through the blood, only locally and only after decades when left untreated does it become capable of destroying adjacent tissue. This patient, a logger who lived in the woods, had come of age during the depression and never accepted anything for which he could not pay. When I met him his entire nose and left eye were destroyed by tumor, and he wore a patch over the left side of his face to conceal his gruesome appearance. He died soon

after of overwhelming infection and encephalitis after the tumor finally spread through his eye socket, opening up a direct pathway for infection to reach his brain.

This case illustrates an important point about access to care for the working poor. This patient only came to see me because the community health center was open to all regardless of income or ability to pay. The patient felt he was using a community resource, not asking for charity, and he was correct. Many people make this distinction.

Most community health centers provide primary medical, dental, behavioral and pharmacy services, and we take the simple approach that dignified, high quality health care is a right in any wealthy and civilized society. Many of our patients sought help from us with this understanding, even after going for years or even decades without seeking care before our health center came into existence.

Other community health center workers have had the same experience. Even so, for the patients who come to us with advanced cancers or surgical diseases, we can only bear helpless witness as, in many cases, they die.

A relatively young woman who was unable to afford routine gynecologic care for nearly 20 years died of a huge tumor which was technically not even malignant, but had grown so large it had already destroyed numerous gastrointestinal and pelvic organs before she came to our office. This was not a subtle problem, and the patient knew that she had it for years. She obviously could have gone to an emergency room at any time. But she

was so worried about financial catastrophe for her family, she kept this problem a secret until it was too late.

There is literally an odor of death that we learn to recognize in our work. The odor hit me when I first walked into the exam room with this young woman, before I even said hello. Since health centers do not usually employ surgeons or oncologists, my job was to refer her to those specialists, where her worst nightmare – not death, but financial ruin for her family – came true.

Two other patients illustrate the same point. Both had aortic stenosis, a common degenerative heart valve disease in which the valve becomes stiff and finally, will not open despite the heart's increasing efforts to pump against it. When this happens, the patient experiences chest pain, sudden loss of consciousness, and usually death follows immediately. Medicine alone is useless for this condition, and can even be harmful. The only treatment for aortic stenosis is valve replacement surgery, which in most cases restores people to a level of functioning that they have not felt in months or years. The recovery time for this surgery takes months, and in most cases patients require close follow-up and lifelong blood thinner medicine with frequent blood tests.

One of my patients with aortic stenosis was a man in his late 50s. He worked for a local transportation company which did not provide paid sick leave or health insurance. When he first came to my office, he could barely walk, and used a cane. The diagnosis was easy to make on the first visit. Within a few weeks, medications were effective at

removing over forty pounds of fluid, thereby giving him significant relief from his fatigue, swelling and shortness of breath. He was able to get rid of the cane, and said he had not felt so good in years. He wanted to believe he was "fixed" but I insisted at every visit that he absolutely required surgery or he would die. He did let me refer him to the cardiothoracic surgeon and he learned what the surgery would entail. Once or twice he considered scheduling the valve replacement, only to postpone it as he could not figure out how he would be able to afford either the direct monetary cost or the time off from work. He died suddenly at work one day, waiting for the right time, about two years after receiving his diagnosis.

I remember another patient who also tried to wait with aortic stenosis. She actually made it to the emergency department when she passed out while driving on the day when her valve finally, inevitably no longer worked. She underwent emergency valve replacement surgery and lived to become bankrupted and disabled by depression.

The financial fears that lead so many patients, including this one, to withhold medical care from themselves, are neither irrational nor trivial. Her husband committed suicide by burning their home with himself in it after it was lost to foreclosure.

Since this is the subcommittee on primary care and aging, I would also like to talk a little about older patients, by returning to the title of my presentation. "Found down" is common medical shorthand used to describe a patient, usually elderly, who has been

brought to the hospital after having lost consciousness at an unknown time, for an unknown reason, while alone.

This scenario is not rare. When it happens, the first thing we try to figure out is the duration of the "down time," as this is inversely related to the patient's chances of having reasonably functioning kidneys, liver, heart and brain tissue. This in turn generally determines whether survival can be expected. The last case I had was only a couple of weeks ago. The patient never woke up before dying days later in the intensive care unit after withdrawal of the ventilator that it turned out she had not wanted in the first place.

Every day in our country, seniors are found down. The risk factor for ending life in this way is being old, sick and alone. Aging and illness are not necessarily preventable, but in our society, being alone at this time of life is widespread. Who among us could not easily end our days in just this way? Most need to pay for simple personal care out of pocket and they simply cannot afford it. Seniors all have medical insurance, but Medicare does not cover low-cost home care which would keep them safely and securely in their homes. This could save their loved ones the anguish of never being able to know what happened, or how much pain and suffering was involved.

Today I understand there is discussion about shifting even more cost onto seniors themselves. This makes no sense. You can see from my perspective that for anyone lacking resources, the natural consequence of any cost shifting or out of pocket costs is

that they simply withhold needed care from themselves, often with devastating consequences.

Our primary care system itself may soon be found down. In case this happens, here is my prediction for explaining the scenario: we will have to admit that we were not able to maintain our primary care work force due in part to this heartbreaking experience of being forced to watch our patients suffer and even die needlessly, even as we knew and advised what they needed, but they could not afford access to the most inexpensive and basic care.

Home care services, dental care, eye care and behavioral health services are among the other types of highly cost-effective support services that can make the difference for many working people between disability and being able to function as contributing members of society.

Let me end with one more patient. This was a young man in his 40s, whose name was not familiar to me when I admitted him to our intensive care unit with a massive heart attack. His cardiogram and blood work showed that the heart attack had started a couple of days earlier, and he admitted he had tried to tough it out at home until he was not only in pain but also found himself unable to breathe. The disease had likely destroyed a large area of his heart muscle, which meant he was doomed to being a cardiac cripple.

I was listed as his primary care doctor and he seemed to remember me. He said a couple of years earlier I had seen him once in the office and advised him to take a low-dose aspirin and beta blocker (blood pressure pill) each day. Both are inexpensive, generic medicines that have been shown to protect patients at risk from stroke and heart attack. He explained that he was a truck driver with no benefits or health insurance, and he could neither afford his medicines nor take time off from work to follow up with his care. Yet to not being able to afford routine care and a couple of generic medicines that might have prevented this heart attack, he would most likely never again work in his occupation.

In conclusion, although I have altered identifying details to protect my patients' privacy, the medical facts of these stories are all true. There are many, many more just like them. Any rural primary care doctor could tell you hundreds of their own. Urban doctors might have a slightly different version, but the moral of the story is this: our health care system and our society can do much better for the people of this country.

I wish the members of this committee all the best in your efforts to create better health and social policies for us all, and thank you very much for the opportunity to provide my perspective today.

*World Health Organization Final Report on the Social Determinants of Health, Geneva, Switzerland, 2008