Public Health, Technology, and Culture

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I am a journalist who believes in narrative journalism, which means I spend a lot of time talking to people and getting their stories. I will confess upfront, I do that in part because I think it's interesting. It's a great way to make a living. People open their lives to me. I get to take down notes and listen to them. I get to be part of their lives for a while, and I get to tell other people about it. It's a terrific privilege. It's wonderfully educational.

But I also believe in it because I believe that you cannot understand the world without talking to people. Statistics alone do not tell us the way the world is. That's particularly true in public policy.

It is one thing to hear somebody tell you that there have been studies to show that people who cannot afford their medical care skimp on the medical care they need. I don't think you can really understand what that means until you've listened to a woman who is a widow tell you about her husband's final months, how the two of them would trade off who took the pills that week because their insurance had run out, and how finally at one point he just stopped taking his pills because he was too proud to let his wife go without her medication and too proud to go to the clinic and beg for his medication. I also think that it's important to tell narratives because it makes a connection with the audience.

If you've listened to any news accounts of the health care debate recently, you've heard these numbers: 18,000 people a year, according to the Institute of Medicine, die because of inadequate health care because of health insurance limitations; 45 million people are without health insurance, or 42 or 47 million depending on which number you believe; and 16% of the Gross Domestic Product is spent on health care.

If you are a reporter and you do narrative journalism, you have a responsibility to be honest. And I don't know that all reporters understand exactly what that means. Honesty has two components. One is to be honest about what you see. It's very easy to listen to somebody tell you their story, take down what they said, and write it down. That is not journalism. If you're a journalist, if you're doing narrative journalism, you have an obligation to figure out whether what you're being told is true.

That's not because people lie, although sometimes they do. People have selective memories. They see one part of a picture. As a journalist, you're doing the first draft of history, and you want your first draft to be good. So you try your best to get different versions of that same truth. You ask for proof. You ask for confirmation. You talk to other people.

The other part of being honest is about context. This is where statistics come in. The truth is if I interviewed every one of you reading this, I assure you I would have at least one story to validate any point in the world on health care policy. I also assure you that there is not one single person whose story perfectly encapsulates any one point. People are complicated. Real life is messy.

So honest journalism gives you context; it presents stories that are emblematic of broader trends, and then it presents those stories with their complications. You don't run away from the inconvenient facts; you embrace them. And when you do that, you get stories that really do tell you something. You get an example, a picture, a poster child who can connect with people and actually make a point and make people think about politics.

You may have heard that we are having a debate in this country now about whether to authorize a program called the State Children's Health Insurance Program (SCHIP). This is a program that was established in the

1990s to give publicly funded health insurance to people—mostly children—who were too poor to get it on their own, but not poor enough to qualify for state Medicaid programs. Congress passed a bill that would have not only renewed the SCHIP program, it would have expanded it. President Bush said he would veto the bill and then he did.

There is a fair amount of opposition among conservatives who argue that the expansion is a deviation from what the program actually stands for. SCHIP was a program meant for poor children only; now the program is expanding to include more people who are better off, who we don't want to be giving assistance to, and who we don't need to be giving taxpayer assistance to.

Every week there is radio address in response to President Bush's weekly radio address. Earlier this year, a 12-year-old boy gave the address. His name was Graeme Frost. A couple of years ago he and his sister were in a very severe car accident and both sustained serious injuries. As a result, they had very high medical bills, which their family could not afford because they could not afford private health insurance. Fortunately for them, they were able to get coverage under Maryland's SCHIP program. So Graeme told his story and said, "Please, this program has helped me. Please renew this program and please expand it so it can help more people."

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For whatever reason, Graeme Frost struck a nerve. Within a few days, some of the people who disagreed with his perspective and the political perspective of the people who wanted to expand the SCHIP program began to dig into his family story. They began discovering facts that they said were a little inconvenient, like, "Did you know that the Frost family owns their own home?" If these people are so destitute that they need government health insurance, how do they own their own home on a block where a house recently sold for $300,000?

Somebody else started looking through the public information available on this family, and it turned out that Mr. Frost owns a woodworking business. He is a successful small business owner from the looks of things. What's he doing on the taxpayer dole?

Somebody else found out that the Frost family enrolled the two children in an expensive hoity-toity best-private-school-in-Baltimore school, a $20,000-a-year private school. What are these people doing on government assistance?

Then a conservative columnist named Michelle Malkin, who became famous for writing a book defending the internment of Japanese during World War II, decided that she would look into the story. She flew to Baltimore, drove by the Frost's home, and saw that there were three cars in the driveway, including a new SUV. Three cars? Why are these people on the government dole?

And finally, somebody who wrote a blog about health insurance said, "I went and priced policies in Baltimore to see how expensive they are. A family could buy a policy in Baltimore for $400 a month. This family is making $40,000 to $50,000 a year at least. They can afford that. What's going on here?"

Of course, if you're going to look into the facts, you need to look at all the facts. Somebody finally did talk to the Frost family and here is what they found. The Frost family does have three cars. One is a beat up old truck that's about 20 years old. Mr. Frost uses it for his woodworking business to haul things around town because, frankly, it's not strong enough to go longer distances. The SUV was a gift. After the car accident, the kids were traumatized. They couldn't go in a small car. So a group of families in the neighborhood got together and bought them a new SUV. They also arranged to have the kids sent to private school on scholarship because the children needed special attention.

The house was bought 15 years ago for $50,000 in an area that was a drug neighborhood. It has since cleaned up, it has gentrified. But they still owe a mortgage on the house. But the fact that they had some money wasn't really an issue. They tried to buy health insurance. But Mr. Frost was a small business owner and Mrs. Frost had a part-time job, so they had to buy it on their own. If you know anything about the individual insurance market, you know that people with preexisting conditions usually can't get insurance. Preexisting conditions? Well, meet the Frost children with their lingering injuries from the car accident. Nobody wanted to insure them.

It turned out that most of the things that were being said about them were wrong, but not all of them because, you see, this was a complicated story. The truth is the Frost family of Baltimore was not destitute. They were not dirt poor. They were not starving. They did own their own house. They did work. They were living an okay, working-class life. But they couldn't get health insurance. And that is the problem we have today.

We have a situation where millions of Americans who "play by the rules," as Bill Clinton used to say, are being locked out of the health insurance system. The story of the Frost family is actually a very good window into what's happening in America. Unfortunately, the story of what happened to the Frost family politically is a very good window into what's going to happen in this political debate.

In my book, *Sick: The Untold Story of America's Health Care Crisis—and the People Who Pay the Price,*[1] I try to tell the story of that debate through a few stories of actual people. Let me mention one at the top, the one about Janice Ramsey.

Janice is a real estate entrepreneur in Florida. She and her husband started a business. When he reached retirement age, they sold the business and she continued to work for it as a consultant. A self-made woman, she

put herself through college taking night classes after her children had grown up. She worked very hard. She prided herself on carrying herself like a professional, even though she grew up in a blue collar family and it took her a while to learn all the tricks of the trade. She is a real spark plug of a woman too, a real go-getter, very fiscally conservative. She paid every bill on time and had a perfect credit rating.

Janice had just one problem: she was diabetic. She learned this at a relatively late age, and when she learned about it, her insurance policy was cancelled. They said that she had concealed the fact. She had switched policies because the one she had was very expensive, as often happens when you buy insurance in the individual market.

Janice didn't conceal anything. She had no idea she was diabetic. She actually had the right to challenge the cancellation of her insurance under Florida law but she didn't know it. She kept trying to look for new insurance. She had the money and was ready to write the check. She wanted to get insurance, but no one would sell it to her, until finally she found a policy through a local association of realtors.

They said, "Here, we have a group. You can get insurance through it." The people who sell the insurance came to her house. They had beautiful brochures. They plugged her into all the nice doctors and hospitals in central Florida; they would cover her diabetes, and it was not too expensive.

Janice was thrilled. She signed up. She paid her premiums. Eventually she started getting calls from the hospitals she had been to. They hadn't been paid. So she called the insurance company and said, "Please, you've got to pay this bill." They said, "Oh yes, we're just reviewing it."

She finally got a call from a bill collector, so she decided to get the state authorities involved. She said, "Please can you do something? My insurance company won't pay." The state had to break the news to her: "Ma'am, your carrier is fraudulent."

Now the good news for Janice is that she had lots of company. This was a nationwide scam. It was the third such wave of scams since the 1980s—all of them targeting people like her who were having trouble finding insurance in the individual or small business market, promising good insurance to people, even if they had preexisting conditions. There was $250 million in unpaid medical bills from this one scam alone. A lot of these people now found themselves saddled with five-figure medical debt, uninsured all over again, and back to square one. This is the nature of our insurance system today.

There is actually a good deal of agreement that at any one time the number of Americans without health insurance is 45 million. It is true that not all of them are uninsured for the whole year. But it is just as true that in up to a 2-year period, 80 or 90 million Americans will at some point go without health insurance. We're talking about more than one-fourth of the American population. And not all of these people are hapless victims. In fact, nobody is a hapless victim. One of the complications of life is that everybody makes mistakes and does things they shouldn't have done. There are people who should get health insurance, could afford it, and just don't get it. But there are also people who cannot—not by any reasonable standard anyway.

And this is going to continue. All the trends that we're seeing are going to continue. Costs will keep going up. The safety net is going to keep weakening. The good news is that as we get a better understanding of genetics and what diseases you're predisposed to, we'll be able to treat you way in advance. The bad news is that the insurance companies will know way in advance what your risks are and will be able to deny you coverage if you apply on an individual basis.

If we turn over our health care decisions to the for-profit sector and don't give them any rules for what they may do, we shouldn't be surprised when they try to make money the way they do. That brings us to the political debate we're having now. The emerging political debate basically looks like this. We have what I would call the

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mainstream conservative position: it's the lawyers, it's the malpractice lawsuits. Anyone who tells you that solving the malpractice problem will solve the affordability of health care either doesn't understand the problem, or is lying. The studies on this are virtually unambiguous.

The big complaint that you'll hear from conservatives is that we have too many mandates on insurance. One of the things they'll say is that it's unbelievable for a state to mandate that Medicaid cover wigs. The state that covers wigs is Minnesota and the wigs are for chemotherapy patients. Wigs are expensive, but Minnesota decided, "You're going through chemotherapy. You should be able to get a decent wig. Many private health insurance programs cover wigs. Why shouldn't Medicaid?" Some mandates are egregious. A lot of them are there to protect the people who need them.

We also hear about consumer-directed health care or, as we like to call it in the health care business, "show us some skin." If you talk to anyone in the corporate sector you will hear these buzz words: "We need people to have skin in the game," which means they think people aren't paying enough for their health care. They consume too much. When I'm in front of a corporate audience, there is always some guy saying, "My grandson had a sore throat, it turned out to be nothing, but they took him for a strep test because it was free. If they had charged for that strep test, he wouldn't have gotten it. This is the problem with health care."

Believe me when I tell you, too many strep tests is not the reason we have expensive health care. Most of the money spent is concentrated on the 20% of people who are really, really sick. The idea of giving people more

exposure to costs really doesn't affect them. Usually the way it works is you say, "You have to pay the first $5,000 of your expenses as a deductible and then insurance kicks in." Well, really sick people pay $5,000 in 2 weeks. They're acting the same as they did before.

The one thing we do know, however, is that people will skimp on medication they need. There have been many studies on this, going back to the original Rand studies in the 1970s. A 2006 study in the *New England Journal of Medicine*,[2] based on data from the Medicare drug benefit, found that if you charge people more for their hypertension pills, they don't take their hypertension pills. Then they show up in the hospital with heart attacks. It's a lot more expensive to treat the heart attack than it would have been to give 100 people cheaper hypertension pills.

That's not to say that having consumers take on some cost is not good, because it probably is. A good health-care system does make everybody pay a little bit. But you should have to pay what you can, not more than you can.

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So what is the alternative? The alternative is universal health care. What does universal health care mean exactly? It can mean almost anything. I think of it like a Chinese restaurant menu. You can have delivery options. You can have a public plan, a choice of multiple private plans, or a combination platter of public and private plans. You can have taxes or mandates. You can try to get money through efficiency. You can try to regulate prices. And you can design the benefits you want. You can make everybody pay nothing and have completely free health insurance. You can make everybody have lots of cost sharing. You can do it in any sort of way.

However, the common elements are that insurance is available to everybody, it's affordable for everybody, and everybody has to have insurance. You do that and you pay for it in a reasonable way. The benefits are that at some decent level, you have universal health care.

When I talk to experts I often hear, "Universal health care is not going to get rid of medical errors and it won't do much right away to control costs." Well, no, it won't. It won't solve global warming either. What it will do is create a simpler system where nobody faces severe financial penalties because they're seeking medical care. That's a pretty big deal. If it does only that, it will be the single biggest piece of social legislation in this country since the 1960s and maybe even since the 1900s.

You can say, "Yes, but if we go to universal health care, how do you know we'll be like France or Germany or Switzerland or one of those countries that covers everybody, but doesn't ration services, like they do in England?" In England, they do rationing. They scrutinize treatments heavily. People wait on long lines.

There is a relationship between a nation's culture and the kind of health care system it has, for better or for worse. The British spend a lot less than we do. Frankly, the British get a lot more for their money than we do. Maybe it's not worth spending all that money on health care. Maybe it is. Either way, that's the British sensibility. They are a low-spending country. They always have been and they always will be. We'll always be a high-spending country, for better or for worse. Universal health care won't change that, not right away.

People here talk about bioethics. Maybe that's a place where we do need to change things. Maybe we do need to stop throwing the health care kitchen sink at everybody late in life. We have to think about what we want to do and what we don't want to do.

But that's going to take time—and when you look at the severe economic and medical hardships that people without insurance face, time is something we don't have. Universal health care would mean a guarantee of economic security and access to the best medical care we have to offer—not just for a privileged few, but for everybody. That would be a pretty big accomplishment.

REFERENCES

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