

Episode: *Ethics Talk: How Consumer Advocacy Groups Advance Health Equity*

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TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics and health and health care. I'm your host, Tim Hoff.

Health care is an expensive, confusing mess. Even with the Affordable Care Act increasing many residents' access to preventive health services and the recent No Surprises Act incentivizing price transparency, patients in the US are consistently left wondering whether they can afford services they just got, need, or will need, or whether getting indicated care for themselves or their families will plunge them into debt. Despite widening political divides, policies to reduce costs have broad consumer appeal and bipartisan support. Some policies that are popular limit what health care organizations can charge for services, allow the federal government to negotiate drug prices, and eliminate deductibles and co-payments that charge people just for using the health insurance for which they have already paid premiums. Without a reliable response to the question of how much will it cost, patients can only guess and hope that the care that they or their families need won't make them a part of the millions of US adults who are in debt because of needed care.

The latest efforts to help curb health care costs focus on increasing the transparency of information. As of January 1st, 2021, hospitals in the US are required to provide clear, accessible pricing information about items and services they provide. They have to do so in two ways. First, by listing a "comprehensive machine-readable file with all items and services" and second, by displaying "shoppable services in a consumer-friendly format." Compliance with these rules has been slow, however, and enforcement is cumbersome. So, patients still face high costs, unexpected bills, and growing debt just because they're patients of the US health sector.

Joining me today to discuss medical debt and its sources, legislative efforts to address rising costs, and how patients can advocate for themselves and their loved ones is Mark Rukavina. Mark is a Program Director with Community Catalyst, a non-profit national health advocacy organization dedicated to advancing a movement for health equity and justice. He is also the Business Development Director for the Center for Consumer Engagement in Health Innovation, where he facilitates business opportunities with innovative health care organizations. Mark, thank you so much for being on the show with me today. [music fades]

MARK RUKAVINA: It's a pleasure to join you today, Tim. Thank you.

HOFF: So, to begin with, can you introduce us, our listeners, to the work that Community Catalyst does and the wider roles that community-based consumer advocacy groups play in changing health care to protect patients?

RUKAVINA: Of course. Community Catalyst, as you said, is a national non-profit organization. We were established in 1998, and our mission is to build the power of people to create a health system that's rooted in race equity and health justice in a society where health is a right for all. Our long-term vision is of a future where everybody has what they need to be healthy and to thrive, and that is regardless of their health status. People should have control over how they live and be able to access comprehensive, quality, and equitable care. Our work is done in partnership with groups working at the state, local, tribal level to build really a strong and powerful health justice movement that's aligned with a broader progressive movement. And our aim is to address factors that affect health and well-being, including issues related to health coverage and health access, economic justice, housing, and other social determinants of health. And we believe that building consumer power is vitally important to establishing a system that is truly responsive to the needs of people in communities across the nation.

HOFF: So, when we talk about health care costs, a lot of people obviously think of, you know, "Oh, I've heard of this sort of No Surprises Act that went into effect at some point." [chuckles] For our listeners who are unsure, that's been in effect since the beginning of 2022. Have we seen actual costs to patients and their loved ones become more transparent with this legislation? And do you have any examples of some successes or failures of this legislation, or is it just too soon to tell?

RUKAVINA: Well, as you said, the law went into effect on January 1st.

HOFF: Mmhmm.

RUKAVINA: So, these so-called surprise medical bills are prohibited as of January 1st. And what that means is for people who go to a provider who's not in their health insurance plan's network previously, prior to January 1st, many people faced very large bills that were quite shocking and surprising to them because they saw a provider that was out of their insurance plan's network. So, as of—and we've seen some data on this—in the first couple of months of the year, more than 600,000 bills were affected by the No Surprises Act protections. That's a tremendous result for patients who otherwise would've faced very expensive medical bills.

HOFF: This is a very data-heavy episode, so this is going to be the first of a few clarifications throughout. The AHIP report that Mark is referencing here claims that there were 600,000 No Surprises Act-eligible claims in the commercial market in January and February of 2022, based on survey responses of the claims that had been processed at the time of the survey. But they go on to clarify that revised estimates using past data on total numbers of claims processed by commercial health plans suggest that there were more than 2 million affected claims in the commercial markets in the first two months of 2022.

RUKAVINA: From our local and state partners, we're not seeing a tremendous amount of information hearing back from them with many cases regarding the No Surprises Act. We think there's still a tremendous amount of work that does need to be done to educate the public of these protections. We trust that providers are complying with the act, complying with the law, and are reaching out to our partners to understand better what's happening on the ground.

There've been some interim final rules issued on the No Surprises Act, and I just want to mention something that might be a surprise to some of your listeners. As I said, this largely

focuses on patients with insurance who are seeing providers who are out of their insurance plan's network. There were some changes made or additions made in the interim final rules to bring some protections to people without insurance as well. And we were really pleased to see those protections put in place. And again, I think this is going to be an important part of an educational effort to let people know that there are protections under No Surprises for people with insurance as well as uninsured patients. So, the final rule prohibits collections when a patient and a provider are disputing the billing process or the bill that was generated from an incident or a procedure. And again, we think these are important protections, and we think that the general public needs to be better informed of these protections.

One way to do that, we believe, would be through funding what are called consumer assistance programs. They provide assistance to people on coverage options, for example. And those programs typically have other essential—what we consider essential—services: language and interpretation, translation services. And they have systems already in place to explain the complex insurance system that exists and the complex billing process. They also have relationships that we believe are important with community-based organizations and residents in their communities. So, they're trusted partners, and they could be part of getting the word out on the No Surprises Act.

HOFF: How can somebody who has questions get in touch with one of these consumer assistance programs?

RUKAVINA: They can go on our website. We have our state partners listed on the website. We have identified resources that have consumer assistance programs. So, it's [CommunityCatalyst.org](https://www.communitycatalyst.org) is our website. They could go there. They could also just do a simple Google search for consumer assistance programs for help with health insurance in their state, and most likely they would identify some of those programs in their states.

HOFF: Mmhmm. So, it sounds like the No Surprises Act is well-positioned to help address some of the issues related to out-of-network care, and as you said in your first response, 600,000 bills being affected is a pretty good start. But we can't ignore the fact that even with in-network coverage, the US still has some of the highest health care costs in the world, and as a result, some of the highest levels of medical debt and medical bankruptcy. So, what should our listeners know about medical debt in the US, how it's accrued, who generally carries it, and how debt can be considered an iatrogenic harm that influences health outcomes?

RUKAVINA: Yeah, it's a great question. So, the No Surprises Act will address some of the medical debt issues, not all of them. Yes, health care is expensive in the United States, and the structure of private insurance in the United States leaves significant out-of-pocket costs for some people. The US Census Bureau estimates that about 17 percent of US households had at least \$195 billion in medical debt in 2019. So, this is pre-pandemic. This is probably going to play out differently over the past couple of years. That's the most recent data we have from the Census Bureau. And some people are at greater risk than others. So, if you look at those numbers across race, it's dramatically higher for Black households, 27 percent as compared to 17 percent for all US households. Twenty-seven percent of Black households have medical debt, and nearly 19 percent of Latinx households have medical debt. So, we see that obviously, certain populations are affected by this. Lower-income households are more likely to have medical debt. Families with children are more likely to have medical debt than families and households without

children in them, and families with a member who's disabled are almost twice as likely to have medical debt.

HOFF: A quick clarification. The data that Mark seems to be referencing here comes from the Survey of Income and Program Participation conducted by the US Census Bureau. That survey found that 19 percent of households carried medical debt in 2017 and also that households with a householder of Hispanic origin were 21.7 percent more likely to carry medical debt than households without a householder of Hispanic origin.

RUKAVINA: There are other sources of data on this issue too. The Commonwealth Fund does surveys on this issue, and their most recent data they found that 23 percent of working-aged American adults—so that's about 45 million working-age American adults—have medical debt or medical bills that they're paying off over time. Obviously, this problem's going to affect the uninsured very, you know, have a very significant effect on the uninsured. About a third of people with no insurance have medical debt. Not everybody who's uninsured uses, you know, seeks medical care. Not everybody with insurance seeks medical care either. So, about a third of people without insurance have medical debt. Many of them, interestingly, are living in states that have not expanded the Medicaid program. So, what we see in those states is that there's a greater number of accounts sent to collection compared to states where Medicaid was expanded.

But it's not just a problem, Tim, that affects uninsured patients. As I said, it affects the insured as well, and about 22 percent of insured people have outstanding medical bills. So, this means just about anybody's at risk of incurring medical debt, again, given insurance deductibles and co-payments and coinsurance, and none of us has a crystal ball and can predict what our health care needs are going to be in the upcoming year. So, not just a problem for the uninsured. It affects people with insurance.

There are certain groups that are at higher risk of incurring medical debt, and it is an iatrogenic problem. There's been language in the literature recently. I think it started with people doing work in the oncology field describing medical debt as financial toxicity. So, we talk about the toxicity of treatments in cancer treatment, obviously, and I think it came to the attention of many providers working in that space that they realized that the treatments that they were providing people that might be saving their lives and might be giving them a better quality of life had other side effects. And one of those side effects was the financial toxicity, that people incurred significant medical debt, and for many of them, debts they were unable to pay. I know I've talked, and we've talked in our work at Community Catalyst, with people in the midst of treatment who say they really had to think long and hard about whether to pursue a particular form of treatment for concerns that they were going to leave their families saddled with debt as a result of the treatment that they received, and in particular, patients with some serious illnesses, cancer being one of them.

HOFF: Mmhmm. Yeah. I just want to make clear the sort of cascading equity concerns of your last statement there, that if Black households and Latinx households, for example, are more likely to carry medical debt, and then that debt influences, especially if it deters the treatments that someone would accept because of the weight of financial toxicity, the end result would be that people from those households are receiving less care, and that ultimately widens existing disparities in health outcomes.

RUKAVINA: Yes, and we've seen that research bears that out, Tim. People who have incurred medical debt are more likely not to seek care in the future because of the bills that

they have. And the interesting thing about medical debt, Tim, it's kind of contagious. It affects not only those individuals, but also their families, as I said. What we know from surveys and the data that are out there, a pretty significant portion of people with medical debt used up all their savings to pay their medical bills. Now, some of them still came up short after that. What do they do next? Oftentimes, they borrow from family, and that's one of the ways in which it's contagious. They borrow from friends, another way in which it's contagious. So, that medical debt can affect not just those individuals, but their family members and their friend groups as well.

For many of them, they also put the, pay the medical debt with a credit card, and that's taking a problem and making it even worse by adding interest rates on top of the bills that they're already struggling to pay. We know, again, from interviews we've done, from the work of our partners, from survey information that's out there, for many people, especially people in ongoing treatment or with a family member in ongoing treatment, they are concerned with preserving the relationship they have with their providers. So, they are oftentimes embarrassed by these medical bills that they have and do things, as I said, that may make matters worse like a put it on a credit card. Many people take out loans against their homes or mortgage their homes to pay off medical bills. So, we think that these are problems that get amplified, really, when people don't have adequate insurance protection, or they don't have adequate resources to pay the medical bills that they had incurred.

HOFF: Sure. I'm going to jump around a little bit here just since you were talking about folks putting medical bills on credit cards. So, there've been some recent changes to how medical debt is reported on credit reports. So, do these changes protect patients?

RUKAVINA: Well, first of all, the Consumer Financial Protection Bureau has been studying the issue of medical debt for many years. So, they issued a report earlier this year saying they were seriously looking at issues, at whether it's appropriate to include medical collections or medical debts on credit reports. There'd been some research that the Consumer Financial Protection Bureau had done. There was also research that was done by some of the credit scoring agencies where they developed new scoring models and found that medical bills or these medical collections on people's credit reports were less predictive of their credit worthiness than were other sorts of bills. And when you think about it, it makes sense. Medical bills are not bills that people necessarily voluntarily incur. It's not your regularly and recurring monthly credit card bill, for example or mortgage or an installment plan at the local department store. These are bills that can come at a time when one least expects them to come. So, the CFPB said that they were going to be looking at whether it's appropriate to include medical collections on credit reports.

Shortly, interestingly, pretty soon thereafter they issued that report and statement earlier this year, the National Consumer Credit Reporting Agencies announced—the big three agencies announced—that they were going to take action on their own, and that as of July 1st of this year, they were going to do two things. One, they were going to remove any medical collection on a credit report with a zero balance due. Now, that might be surprising to some people listening to the podcast that those accounts stayed on a credit report, and it might be surprising for people to learn that those accounts actually drag down a person's credit score. But in fact, that's true. And we've seen time and again, the CFPB, the Consumer Financial Protection Bureau's own research, has found that medical collection accounts on credit reports are the most common type of account on a credit report. The next most common, and nearly, well nearly 60, 58 percent of the collection accounts on credit reports were medical accounts in 2021.

HOFF: One final point of clarification. The report that Mark is referencing here points out that 58 percent of bills in collections and on people's credit records are medical bills as of the second quarter of 2021.

RUKAVINA: And the next most common reported collection account on a credit report was telecommunications, so phone bills, cell phone bills, etc., and that was 15 percent of collections, so dramatic difference, much, much out of proportion to the debt that people carry. So, it has a real detrimental effect on people's credit scores that these accounts are on their credit reports. So, how do these accounts end up on people's credit reports? Well, it may be that person received service. Could be that the provider and the insurer or the patient and the insurer are still going back and forth around the adjudication of a claim. The provider might send that bill to collection, the collection agency might report it, and in the meantime, that bill could've been paid by an insurer. And it will appear as a, you know, if all of the proper actions were taken, it could appear on a person's credit report with a zero balance due. Or it could be that the person was just waiting for the amount to be determined, the amount that they owe, as opposed to the insurer or any discounts that providers might be providing to them have all been accounted for, waiting for that amount that they owe to be determined before paying the bill. And again, in the intervening time between, while the negotiation's going on and the bill maybe having been paid directly by the consumer, it might've been reported, and again, end up on a person's credit report, so.

And the other way, and we hear this commonly from or typically hear from both patients and people in the collection industry, that oftentimes they'll call the patients, and the patients will say, "Oh, okay. Now, is that the amount you've determined and the provider's determined and the insurer has determined I'm obligated to pay?" And they pay those bills. But once they hit a person's credit report, they remain there as part of a person's credit history, even if the amount due is zero.

The other change they made as of July 1st, Tim, was to wait one full year before reporting medical accounts on credit reports. And again, part of that is just the insurance adjudication process. You probably know, many listeners do, that sometimes it takes a while for medical claims to work through the process. So, this one-year waiting period extends it from what had previously been 180 days or six months. And we think that's going to give consumers much more time to kind of work out what's owed and to pay those bills. Those two changes are significant. They went into effect July 1st.

As of the first part of next year, they will also, the credit reporting or the consumer reporting agencies, will not include medical debt of less than \$500. According to their materials, these three changes combined, not just the ones that took effect as of July 1st, will remove about 70—seven-zero—70 percent of medical collections on credit reports. So, these are significant. We think, we'd like it to go further. We don't think it's appropriate for medical collections to be on credit reports, but these are very, very important changes that should have immediate effect on some people who should see their credit scores increase once those accounts are removed from their credit reports.

HOFF: Which protections exist for patients who are still facing medical debt, and which self-advocacy strategies—you mentioned following up on your own credit report and things like that—what other strategies should we all learn how to wield when we or our loved ones are patients?

RUKAVINA: For insured patients, and many of us pay significant amounts of money in premiums each month, either directly or indirectly in combination with our employer, and we

want to make sure that the insurers are paying what they should be paying for any care or treatment we've received. Don't take no for an answer. Sometimes claims get rejected, but if they're challenged, they subsequently get paid. So, if you think something should be paid, contact the insurer. There's oftentimes an internal review process that people can pursue within the insurance plan to challenge the payment or the nonpayment of a claim or the amount of the claim that was paid. Pursue those options. There are oftentimes, and states have various agencies or departments oftentimes called Departments of Consumer Protection or Patient Protection depending upon the state you're in, where an external review of a claim is also possible. Pursue that important consumer protection. So, whether insured or uninsured, many providers have what's called financial assistance or charity care policies. This is absolutely true for non-profit hospitals. It's actually required under federal law for non-profit hospitals to have financial assistance policies. And those are important safety net programs or policies for patients that receive care at hospitals, and they should take a look at the hospital's financial assistance policy and apply for those policies. That information for non-profit hospitals should be clearly posted on hospital websites and available to people that ask for that information.

Don't take no for an answer. I mean, we've heard from patients who said they called a hospital and were told, "Oh, you probably don't qualify for financial assistance, anyhow." Apply. Apply. Get an application. Provide them with the information they need to make a determination on financial assistance. Don't be discouraged by somebody on the other end of the phone who tells you you might not qualify. Because for many people we've worked with, that is not the case. People do qualify. They oftentimes don't know of these important protections that exist.

But another really important protection, especially for people without insurance, is to make sure that they're fully informed of any coverage programs that exist for them. And that might even, you know, they can access many of those programs even after having received services, for example, from a provider or a hospital. Medicaid, the Medicaid program, is a very important protection for people and oftentimes includes retroactive coverage. And then coverage under the marketplace, private insurance coverage that is provided under the marketplace. Those are all ways in which people can advocate for themselves.

And then talk to the providers. Don't ignore bills. I mean, that's just, that is our basic advice to anybody that we talk with and our partners as well with medical bills that they're struggling to pay. Talk to the provider. The provider, in all likelihood, wants to also preserve a good relationship with you as a patient, for example. So, talk to the provider. See if you can arrange an extended payment program, for example, with the provider. Some states require this, for example.

HOFF: Those all sound like really good strategies. Thank you. And I'm glad you specifically brought up speaking directly with clinicians, since clinicians are often as in the dark as patients about what health care costs, but they are obviously interested in helping where they can. So, what should clinicians know and do to help patients navigate iatrogenic harms of financial toxicity, including the incursion of medical debt?

RUKAVINA: Yes, great question. And there are resources out there for physicians and other clinicians. The American College of Physicians has some very useful resources, Cost of Care Resources. And those resources help clinicians talk with patients about, provide some guidance to clinicians on how to talk with patients on the cost of their care and very good resources that were developed by clinicians and with patient input. How to

identify patients that might have financial challenges, steps that they can take to help ease that problem for patients, helping them identify resources that exist that patients might otherwise not be aware of. So, American College of Physicians, Cost of Care Resources, that's one place I would point any students or providers to very, very good resources that they have developed.

It's interesting because in a recent survey that was done, a national survey, about half of people, when asked if they could pay an unexpected \$500 medical bill, nearly half of people said they couldn't do that. But when you couple that with this, what we know about medical debt and financial barriers to care, then it's concerning. And I would imagine it's going to be quite concerning for any clinician that wants to keep a patient in care. So, clinicians should really look at those resources from ACP.

They should also understand what things cost. There are other campaigns out there focused on clinicians. Choose Wisely is one. There are others, you know, Cost of Care, other resources for physicians and other clinicians. Understand value-based care and whether a procedure is of high value, and really kind of take these into account when providing medical advice and when treating patients and in talking with patients about what some of the implications must be. Obviously, very important for people to be treated and that their needs are met, but also forewarning them that there may be costs incurred for the care that they receive. So, understanding what things cost. Prescription drugs are a good example of this. Do you need a brand-name drug, or is there a generic that might be equally as effective? That's just one example.

The other thing clinicians can do is understand whether there are resources within their own institutions. If they're working in a physician group or in a hospital or a clinic, are there other people in those entities that can help people identify coverage options, for example, or apply for financial assistance or charity care that that institution might be providing? So, become familiar with those programs within your own, a provider's own institution, I think, is also an important step for providers, clinicians to take to help people avoid incurring medical debt and all the problems that come with it. [mellow music returns]

HOFF: Mark, thank you so much for your time today and for your work with Community Catalyst. It's been great having you on the show.

RUKAVINA: Well, Tim, you're welcome. I appreciated the opportunity, and I hope this information is helpful to your listeners.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Mark Rukavina for joining us. Music was by the Blue Dot Sessions. To read the full November issue for free, visit our site, JournalofEthics.org. For all of our latest news and updates, follow us on [Twitter](#) and [Facebook @JournalofEthics](#), and we'll be back soon with more *Ethics Talk*. Talk to you then.