Medical Debt in Their Own Words: Qualitative Interview Results

“I have a great fear of medical debt. So, I just avoid it like the plague. It’s depressing because I know that in the event that something truly is going on with me, I’m pushing it down to avoid being in debt when it could be something serious.”

“To get a bill after I’m calming down and starting to feel normal [after being hospitalized], it felt like the carpet was ripped from underneath me again.”

“It gets overwhelming because even though I have a job and I have this insurance that I’m paying for, I have other bills and expenses that I’m trying to take care of. I just don’t have the money to pay this bill.”

INTRODUCTION

Workers are feeling the weight of their medical bills as acutely as ever, regardless of the impact on their credit, which has been mitigated by recent changes to how credit bureaus report medical debt. Therefore, efforts to reduce these debts and improve access to affordable, effective healthcare remain critically important.

This brief profiles the results of our in-depth conversations with 10 individuals who volunteered to share their experiences with medical debt and the healthcare system. The themes to emerge from these interviews both reinforce and build on our headline survey findings that insurance is not sufficient to avoid medical debt due to unaffordability of coverage and confusion around insurance, and that medical debt impacts workers’ mental, financial, and physical health, largely due to deferred care.
KEY FINDINGS

Impact of Medical Debt:

1. **Healthcare is unaffordable and overwhelming** the moment workers have even a small unexpected medical issue.

2. **Medical debt leads to stress**, deferred care, difficult spending trade-offs, and the postponement of financial and other life goals.

Employer-Related Challenges:

3. **Workers report that they receive insufficient explanation** of their benefits and are frustrated by their limited visibility into their employers’ decision-making process around plan choice and contribution amounts.

4. **Workers struggle with insurance instability** caused by changing employers, getting laid off, or employers changing their insurance provider every year.

Health System-Related Challenges:

5. **The cost of healthcare is extremely unpredictable** and is exacerbated by poor communication around medical billing practices, such as sending bills months apart following treatment.

6. **Patients struggle to find trusted, in-network providers** with timely appointment availability.

Several of the interviewees we spoke to who identify as Black women shared similar experiences about not being listened to by their providers in the past, which resulted in symptoms and diagnoses being ignored. At best, this felt horrible and dismissive, at worst it resulted in an emergency room visit. This made finding and retaining access to providers they trusted—and who ideally looked like them—even more important. “I think that’s why people don’t necessarily go to the doctors: because they feel like they’re not being heard. And then they have to pay a bill on top of it.”

7. **Financial assistance at nonprofit hospitals has a high barrier to access due** to obfuscation and a burdensome application process, making people feel that the system is designed to confuse them and to squeeze money out of patients.
WHY THIS MATTERS FOR EMPLOYERS

Our conversations with interview participants highlighted how damaging medical debt is for workers. While insurers, brokers, PEOs, medical providers, and policymakers absolutely need to play a part in solving this problem—our conversations confirmed that employers are independently well-positioned to have a meaningful impact on workers' experiences interacting with healthcare and avoiding medical debt.

An employer benefit isn’t truly a benefit if people don’t know how to use it, don’t have the cash flow to make it work for them, don’t feel like it is right for them, or don’t feel like it was chosen thoughtfully. But by improving their benefits offerings and HR practices, employers can change these “don’ts” into “dos” that will create access to affordable healthcare and reduce medical debt.

Addressing medical debt is important not only for workers’ overall health, but also for businesses’ bottom lines. Reducing employees' medical debt burdens will not only improve their financial, physical and mental health, but is shown to in turn deliver a meaningful ROI for employers' healthcare and benefits spending, and increase employees’ productivity, positive feelings about work, feelings of being cared for, engagement, and job loyalty.
THE STORIES BEHIND THE THEMES

Michelle is a new mom living in Baltimore and working as a lab tech. Over the last year her pregnancy-related medical bills stacked up, including from heart complications and an emergency C-section.

Kendra works as a program manager for a nonprofit. Last year, she was diagnosed with systemic lupus after struggling to get a diagnosis for several years and racking up medical debt in the meantime. Her annual healthcare costs are now over $20,000, reflecting the unaffordability of healthcare for the 51.8% of Americans with at least one chronic illness.

Patrick works full-time doing maintenance for a hotel. In 2018 he fell off a ladder while trimming a tree overhanging his house and broke two vertebrae, resulting in a $2,100 hospital bill in collections—even after being approved for partial financial assistance.

Ayesha has worked in nonprofits her whole career, and currently works at an organization that provides services to those struggling with intimate partner violence. She is not only an advocate, but a survivor of intimate partner violence herself. One incident put her in the hospital and resulted in medical debt that was duly financially and emotionally painful.

Below, we dig deeper into a selection of the common themes and stories that reflect the challenges of those who are covered by employer-sponsored insurance. To read about the themes and stories that are more relevant to hospital stakeholders, check out RIP Medical Debt’s brief here.
1. **Healthcare is unaffordable and overwhelming the moment workers have even a small unexpected medical issue.**

**Michelle** “Even while I was working, the bills were hard to manage - but after I stopped working, I just couldn’t pay. When you’re in survival mode, and you don’t necessarily know how you’re going to pay your bills it’s like okay, well, I don’t have the money to pay this medical bill right now.”

**Kendra** “[Systemic lupus] mostly affects young women and this is the amount of money that we’re expected to pay every year out of pocket, even with great insurance. And there’s like no way that we can cover that unless you have a trust fund. When you’re 26 you’re working at an entry level job and you have a ton of student debt. It’s just not realistic at all.”

**Patrick** “You know, it feels like I’m already spending enough money just to have insurance and if I go to the doctor, insurance isn’t going to cover 100%. Like, even though you’re paying for [insurance] if you get sick, you have to pay more. You know, it’s just the injustice of it. Even my monthly ibuprofen for my back has doubled, which I mean $16 instead of $8 is not that big of a deal. But I’d be lying if I said I didn’t think about canceling my prescription. When you make like $12 an hour and your electric bill is almost $400, there’s no room for extra stuff. You know, it’s not like I’m taking my family out to eat or anything.”

**Ayesha** “I know that they deserve payment. But is there a way to cover the instances when there are extenuating circumstances, for a person like me? I’m not coming in for a routine situation, I’m actually coming in for an emergency where I was hurt because of a crime that was convicted on me. And having a medical bill feels overwhelming even more so because I’m behind everyone else who has had more consistent income.”
2. Workers report that they receive insufficient explanation of their benefits and are frustrated by their limited visibility into their employers’ decision-making process around plan choice and contribution amounts.

Michelle “I think I went for the high deductible plan thinking that oh okay if I put away money in HSA, it will work. And it really just didn’t, it just was never enough. If you already have a high deductible plan because it may be cheaper than getting other insurance, you’re just not going to have the money to put in the account. Even going into it, one of the managers said that it isn’t necessarily the best medical plan that they have. And they were a very small business, about 30 to 50 people worked there. So I think, you know, the health plan probably wasn’t the best for people.”

Kendra “I think [employers] could be more transparent about the plans that they offer. So, you know, they, they just said, your options are United Healthcare, we’ll reach out to you with all the details. And that was it. So there, you know, there wasn’t any information given about why they chose that plan, or even the way that that plan works, they just pass that off to the healthcare company.” Additionally, “the insurance offered through my job is just not good in this area (on the border of DC and Maryland)...and has a high deductible for medical procedures so I had to also get the gold level plan through the marketplace [for $500 a month] that is the most widely accepted in this area.”

Patrick “The company I work for has been fairly good about sending people out when it’s time for open enrollment and they’ll go through the brochure with you. But I’m bad about internalizing that kind of stuff. Some studying in advance would do me a lot better because I’m sure the information is there somewhere. But I’m not interested in it until there’s an emergency and then it’s too late for me to sit and do some deep reading before I make a decision. If I’m going to the doctor’s office, and it’s not for a scheduled routine visit, then something’s badly wrong and money is the last thing I’m worried about.”

Ayesha “In the nonprofit world, it has never really felt like insurance was like a reward. It felt like, oh, well, we’ll just check off this box and say that we have it but for whatever reason, like we’re not going to make it beneficial to you. We’re not going to consider you, the things that are important for your life, your family balance, so that you can actually continue to work.”
3. Medical debt leads to stress, deferred care, difficult spending trade-offs, and the postponement of financial and other life goals.

Michelle “When I did have a high deductible plan, if I didn’t necessarily have to go to the doctor, then I wouldn’t go - even if I should have gone. I’ll try to hold off as long as I can from going to the doctor. I think it does make people feel bad when they don’t have the cash flow to pay for it because it’s a cycle of, well, ‘if I don’t have the money to pay for it, then I shouldn’t go to the hospital.’ Because I think most people do want to pay their bills.”

Kendra “The stress of not being able to afford medical care worsened my condition significantly. By the time I actually got my diagnosis, I had permanent organ damage. I’ve seen people in my life die because of not being able to access care and as someone with a serious chronic health condition, being able to access care is extremely important to me. So I’ve had to make life decisions that I didn’t want to because I knew that I have to find a way to pay for my health care. So everything else is always on the backburner. For example, at the time that I had the [diagnostic] procedure, I wanted to move and get my own apartment, but once I had that debt, I couldn’t anymore. And since I was going through health challenges, I couldn’t put in more hours of part time work so it was extremely difficult and took a long time to save up enough money to pay off that bill. I wasn’t able to move until this year, two years later.

Patrick “I feel like the system is designed to confuse and frighten you. I’m afraid to go to the doctor anymore than I absolutely have to. I’m fairly sure I had a pretty bad ear infection a couple weeks ago, but there’s no way in hell I was going to go to the doctor unless it started bleeding or something because I don’t want to deal with more medical debt. And that’s sad because I have insurance, I should be able to go to the doctor.”

Ayesha “I’m always trying to choose what to do - things that shouldn’t necessarily be choices like making sure that I have glasses, making sure my children have glasses, making sure that my children have braces. I have to make decisions like no, we’re not going to do that now. And I’m juggling, trying to figure out another solution...Also, it’s a dream of mine to have our own home. I’ve been learning about it and investing in my education about homeownership, but it feels like some of the bills that I have to overcome first are pushing that date forward. And it seems unfair, because, you know, 5 years goes by, 10 years goes by and I don’t feel closer to my vision for myself and my family.”
WHAT CAN I DO?

Building on the recommendations proposed in our previous briefs, the solutions that interviewees expressed wanting from their employers included:

1. **Equip employees with resources for estimating their annual healthcare expenses** (e.g. this calculator from Optum)

   “A big challenge is navigating insurance and anticipating costs. I’ve never heard of any doctor giving me any idea of what it was going to cost up front for anything. ‘Oh, we’ll have to submit it to the insurance first.’ Unless it’s just a co-pay for a regular visit, it could be $5, it could be $1,000, it’s a complete toss up.”

2. **Explain thinking behind provider choices and pricing to promote transparency and trust**

   “I feel like why y’all switching so much? But they’re just like, ‘Oh, we’re trying to find the best rate.’ I’m like, ‘No, you guys are probably cheap.’ I guarantee for 2024 when we have our benefits meeting they’ll have switched again.”

3. **Ensure there is a clearly designated staff member or consultant available to answer questions related to insurance coverage and healthcare system**

   “So with my job, I have medical insurance, and then they also offer different types of insurance. But our HR director didn’t even know the types of plans that they offer, because they just don’t think about sharing that with employees, they just expect the insurance companies to communicate everything.”

4. **Provide a separate and additional training session for anyone to enroll in an HDHP to ensure they understand the implications, how they can make best use of an HSA, and offer financial support so they have the cash flow to make it work.**

   “Yeah, I think having a high deductible plan is just hard. If you don’t have enough to put away it’s not going to work. I really think companies need to absorb a little bit more. You’re not even paying your employees enough. If it’s a high deductible plan, and you’re not paying employees enough to contribute to an HSA, your job is not really done.”
5. Prepare employees with expectations around billing and how to ask for itemized bills

“When they’re going through the document it would be nice to just have maybe a section about billing, like how to understand them, like here’s an example of an itemized bill or even questions to ask.”

6. Provide information about hospital financial assistance policies in case any employees are eligible.

“A lot of people don’t know about [financial assistance]. I even asked when I spoke with one of the financial folks. I was like, Are people aware of this? She’s like, no, a lot of people don’t know about it.”

7. Provide access to financial coaching as a benefit

“I haven’t had to adjust my financial goals, only because of my great financial coach. She helped me call them about a payment plan so I didn’t have to touch my emergency fund. But the whole reason why I had it is because of working with my financial coach so I’m thankful I didn’t have to touch it.”

Stay tuned for our final brief, which will focus on a few key recommendations for employers that have the greatest potential for impact.
PROJECT BACKGROUND

Neighborhood Trust and RIP Medical Debt are partnering to generate awareness, understanding and solutions that enable employers and hospitals to do their part to reduce medical debt burdens, specifically among lower-wage workers. This work will bring the perspectives of low-income workers to the forefront of discussions about medical debt and health benefit designs. Phase 1 of this project entailed surveying 230 individuals about their experiences with medical debt, the results of which are profiled in our previously published briefs.

This brief represents Phase 2 of the project, for which we conducted 10 qualitative interviews with low- to moderate-income volunteers. They have an average annual income of $46,000, 7 of them identify as Black or African American, 1 as two or more races and 2 as white. 9 of them have insurance through their employer, and 1 is disabled with Medicare. They live across the country in Texas, New York, Maryland, Georgia, Tennessee, South Carolina, and Mississippi. Each interview took up to an hour and participants were compensated $50 for their time. For analysis, 2 coders from each organization analyzed 5 of the interviews to ensure inter-coder reliability and to account for biases. We then consolidated findings before separately identifying and labeling the top themes to emerge from the 10 interviews.

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Thank you to our interview participants for their time and candid contributions.