




Voices of the Underinsured

Kansans Tell Their Stories

KHI/10-03 • April 2010

Kansas Health Institute

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The Kansas Health Institute is an independent, nonprofit health policy and research organization based in Topeka, Kansas. Established in 1995 with a multiyear grant from the Kansas Health Foundation, the Kansas Health Institute conducts research and policy analysis on issues that affect the health of Kansans.

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On the Web

An electronic version of this publication,

along with additional information about

The Underinsured in Kansas project

is available online at

www.khi.org/underinsurance.

Introduction

Most Kansans have health insurance coverage but, for many, it isn't enough to protect them from the financial strain of paying for the health care they may need. In response to these financial pressures, some underinsured Kansans make difficult decisions to postpone or forego necessary medical care. Others struggle to pay providers, which puts them at risk for accumulating medical debt, one of the most common causes of personal bankruptcies.

Being underinsured means that one's health insurance is inadequate to address the financial expenses associated with health care services, resulting in financial strain, medical debt or postponing needed care due to cost.

Provisions in the nation's new health reform law that limit out-of-pocket expenses and require comprehensive health insurance benefit plans are intended to help address some of the issues associated with underinsurance. However, these reforms won't resolve the problem of underinsurance, leaving it an ongoing challenge for policymakers at the state and national levels.

The Kansas Health Institute began *The Underinsured in Kansas* project in 2008 to better understand how Kansans are affected by the limitations of their insurance coverage. The project's findings, detailed at www.khi.org/underinsurance, offer the most extensive Kansas-specific look to date at how being underinsured can affect people on financial, medical, social and emotional levels.

> While each profile tells a different story, the 10 stories share a common theme: what happens when health insurance coverage is not enough.

Each underinsurance situation is the result of circumstances that cannot be explained by statistical data alone. So, members of the KHI project team traveled the state to conduct 10 in-depth interviews with underinsured Kansans. The interviews provided the material for this *Voices of the Underinsured* report.

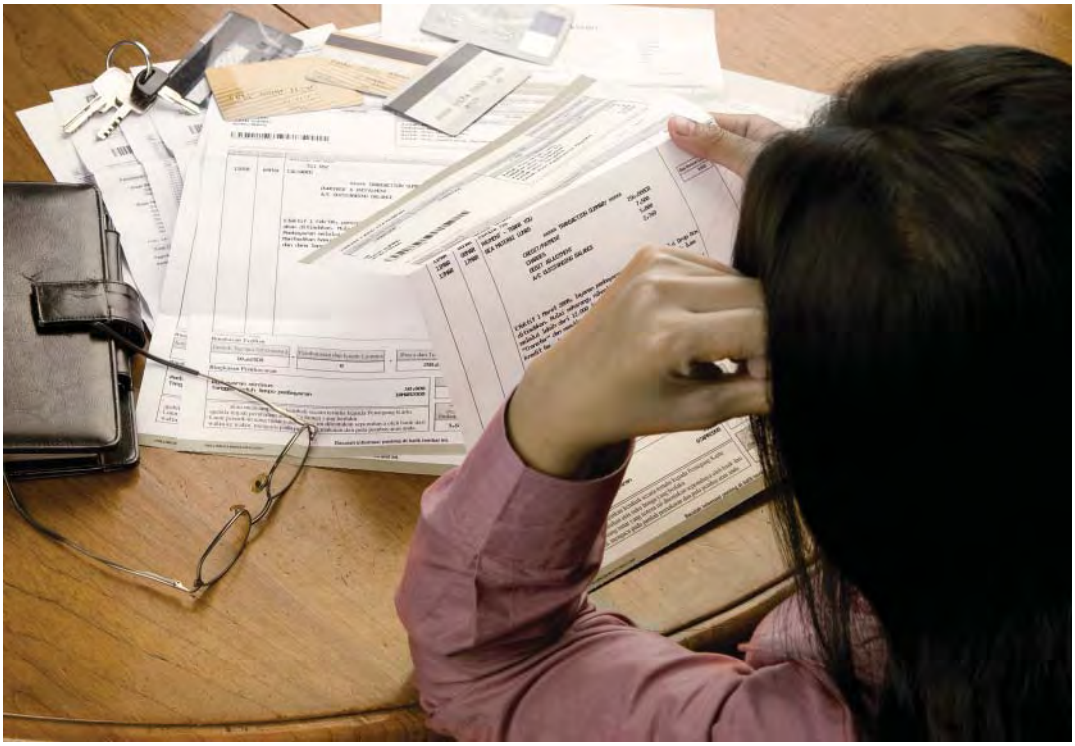
The stories that follow are those of the people interviewed and represent their perspectives on the issues and the situations they experienced. The facts in their stories were not independently verified and the names of the participants and some other specifics were changed to ensure their anonymity. The 10 stories are representative of issues commonly faced by underinsured persons; but, because of the limited number of interviews, they are not statistically representative of all underinsured Kansans.

Each story is supported by a policy note that provides factual information linking the issues raised in the story to a broader policy context.

While each profile tells a different story, the 10 stories share a common theme: what happens when health insurance coverage is not enough. The lives of these 10 individuals were significantly changed when health care costs or services not covered by insurance led them to either postpone or forego needed or recommended care or pushed them into debt or bankruptcy.

The report reminds us that almost anyone — the young and old, the employed and unemployed, the sick and healthy — could find themselves underinsured and at risk for the kind of health and financial hardships illustrated in these stories.

"When you walk around knowing that you owe people money and you can't pay them, that's a really angst-causing situation."



Managing Medical Debt: Tracy's Story

When Tracy and Tom married about two years ago, they hoped to one day take over the family farm from Tom's parents. So they worked on the farm to learn the business and prepare for that day, which they hoped would be sooner rather than later.

And when the young couple welcomed a baby into their family, it seemed that the pieces of the life they had envisioned were starting to fall into place.

Tom's accident wasn't a part of that vision.

But when it happened, the couple believed the small business health insurance they had stretched their budget to purchase would be adequate to cover whatever procedures were needed to treat Tom's injuries as well as diagnose an intestinal disorder he had developed.

"We felt comfortable taking care of his health needs because we thought we were covered," said Tracy, who was 25 at the time of the interview. "Then, we realized that what you think is not such a big deal adds up quickly. It becomes an astronomical number when you are paying radiologists, doctors, technicians and different hospitals."

"We were absolutely overwhelmed with medical debt," she said. "Everybody wants a $60 or $70 payment monthly and we can't do that. By the time you pay that huge premium every month, there's not a whole lot left to make those payments," Tracy said.

Providers eventually turned the bills that Tom and Tracy couldn't pay over to collection agencies, a turn of events that stressed the couple both financially and emotionally.

"My husband and I were raised to take our responsibilities very seriously," Tracy said. "When you walk around knowing that you owe people money and you can't pay them, that's a really angst-causing situation."

But the bills kept coming and so did the demanding phone calls from collectors.

"We received several nasty phone calls a day from hospitals, doctors' offices or people representing them," Tracy said. "They act like I'm skirting my responsibilities but they don't understand that I have to make choices. Every month I pay the health insurance premium and buy groceries, and then whatever's left gets split up between everyone. They don't understand that we're trying."

The financial hardships strained the couple's marriage and their relationships with other family members and made it impossible for them to assume operational responsibility for the farm, forcing Tom's parents to postpone their retirement.

"This has really frustrated his parents as well because it's disrupting their lives, too," Tracy said.

The mounting pressures also took a toll on Tracy's health, which had always been good. She became depressed and started overeating as a coping mechanism.

"My husband didn't eat and I ate myself into oblivion," she said. "That's how we deal with stress. The depression caused me to put on a lot of weight. With that came high triglycerides and blood sugar problems — prediabetes."

Tom's stress led to high blood pressure. Both needed care for their conditions. But their financial problems made getting it more difficult.

"We had to change providers to get care because we owe one place too much money," Tracy said. "We made paying them [the new provider] a priority so we can continue to receive care if we need it, which sounds terrible but you have to have a place to go if you have to have care."

The couple attempted to manage their medical expenses, sometimes at a risk to their health. Tracy stopped taking her antidepressant because the co-pay was too high. Tom switched to a generic blood pressure drug, often taking only half a dose. Both also took second jobs while continuing to work on the farm.

Still, at the time of the interview, Tracy was more hopeful about the future. The fact that Tom — after waiting a year — would soon be eligible to purchase less expensive but more comprehensive insurance through his employer was among the biggest reasons.

"We're on the uphill," Tracy said hesitantly. "We're doing better."

Policy Note

Like Tracy and Tom, most Kansans have out-of-pocket medical expense. These expenses include deductibles, co-payments and coinsurance. The amounts vary depending on the policy and often are slightly higher in the small group market.

According to the 2008 Medical Expenditure Panel Survey, average co-payments, the fixed dollar amount Kansans pay each time they receive specific medical services, is $24 for small group insurance compared to $22 in the large group market. The average coinsurance, the percentage of the medical expense Kansans pay for each service after they meet their deductible, is almost 22 percent in the small group market compared to approximately 20 percent in the large group market. These averages only represent Kansans working for private-sector employers.

Individually, these averages may appear relatively nominal but out-of-pocket expenses can add up when a policyholder sees multiple providers. For example, KHI recently conducted a study of 100 underinsured Kansans. Among respondents who reported their spending on co-payments, one-fifth paid $400 per month within the first five months of 2009.

"It is really good coverage. It's just that I have many conditions and when you go [to the doctor] constantly, it really starts adding up."

Cost Concerns Dictate Decisions: Carol's Story

Carol's story is not unique.

She's among the millions of Americans and thousands of Kansans who have accumulated medical debt because they suffer from multiple chronic diseases and can't afford to pay the portions of their health care costs not covered by insurance.

Carol, 44, purchases health insurance through her employer, a Topeka social service agency. She pays $120 a month for her portion of the premium. Her policy requires her to meet a $500 deductible and then pay 20 percent of the costs for many of the health care services she receives. She is also responsible for a $25 co-payment every time she sees a doctor and a $15 co-payment when she fills a prescription.

When interviewed, Carol described her health insurance as "really good." But, she said, what she was paying to treat her arthritis, high blood pressure, high cholesterol, neuropathy and a bladder disorder was more than she could afford.

"It is really good coverage. It's just that I have many conditions and when you go [to the doctor] constantly, it really starts adding up," she said.

A round of tests conducted just before the interview added to Carol's growing list of medical and financial concerns. The tests confirmed that she was also suffering from fibromyalgia and sleep apnea.

"I've just been through test after test," she said, recalling the expensive MRIs and bone scans she underwent.

Concerned about mounting debt, Carol started making health care decisions based on how much they cost, not what was best for her health. She postponed treatments for her bladder disorder because "they were so expensive." And she made month-to-month decisions about which of her many prescriptions to fill.

"I would say, 'OK, this month I'll get this prescription but I can't refill this one. It's going to have to wait to the next check,'" she said. "I would think, 'OK, what is the most important?' I would go without my high blood pressure medication and I would start swelling. You could push on my ankles and legs and see the water. So, I'm thinking, 'OK, this is not good. I can't skip my high blood pressure medication.' Then you go to the next one and think, 'Maybe I can go without this.' I ended up hurting my health."

Carol considered taking a second job, but concluded she wasn't physically up to it.

"It has come into my head many times," she said. "I could probably pay off things. But there is just no way. By the time I'm done with my eight-hour job, that's it for me."

Realizing she had to do something about her debt, Carol tried to arrange payment plans with her providers. Some were willing, some were not. Eventually, many turned her outstanding balances over to collection agencies.

Carol said she felt "hounded" by the bill collectors, one in particular who frequently called her at work.

"I was in my cubicle where everyone could hear my entire conversation," she remembered.

Facing limited options, Carol worked with a financial company to consolidate her $30,000 debt so that she could make a single monthly payment. But she said the plan didn't work because, "They were taking out so much that I couldn't pay other bills."

Finally, believing that she had no other choice, Carol filed for bankruptcy.

The bankruptcy provided her with a short-term solution to her debt problem. But it didn't address the underlying factors that had caused it: Despite having "good" insurance, Carol was unable to afford the care she needed for her multiple chronic conditions.

At the time of the interview, with her debts again starting to mount, Carol said it was hard to feel optimistic about the future.

Policy Note

A study by the Center for Studying Health System Change found that, in 2007, 20 percent of U.S. working adults with chronic conditions who were privately insured had problems paying their medical bills. Like Carol, many of these individuals' medical needs were delayed or unmet due to cost of care: 17 percent reported going without needed care, 43 percent delayed care and 45 percent did not fill a prescription because of cost concerns. Studies have shown that delayed care or unmet medical needs can have significant health consequences for those with chronic illness, resulting in the progression of illness and increased hospitalization.

Federal health reform attempts to address out-of-pocket medical expenses by establishing limits on these expenses. These limits will apply to health plans offered in the exchanges and in plans offered in the individual and small group markets. The exchanges will provide a place people can compare policies, shop for health insurance and, for some, receive premium credits and cost-sharing subsidies.

"We had made our retirement plans and they just weren't working out the way we had hoped."

Unprepared for Benefit Changes: Leonard's Story

Back in 1992, when Leonard was trying to figure out whether he could afford to retire from his job as a chemist, his employer's commitment to provide health insurance as a retirement benefit proved to be a key factor in his decision.

Leonard, who was 78 at the time of the interview, said that things were fine for several years after retiring. His former company, one of the nation's oldest and best-known, made good on its promise.

But that changed in 2006. Leonard's former employer notified him that he would have to start paying for a greater portion of his and his wife, Jan's, health care costs. Two years later, the company told the couple in another letter that they had to start paying part of the monthly insurance premium and that over time their share of the costs would increase until they alone were responsible for maintaining the policy.

Leonard was alarmed and confused by the correspondence. He was concerned that maybe he didn't fully understand the changes being made to his policy.

"I could read you a paragraph of their communication and you would say, 'What did they say?' I almost had to have an attorney and an English major as an interpreter for all the language about these changes," Leonard said. "So, I became very concerned."

However, one thing was clear: Leonard and Jan had to immediately start paying $134 of the monthly premium that his former employer used to pay in full. For the couple, whose retirement income consisted mostly of Social Security benefits, the cost was a significant and unanticipated increase in their monthly expenses.

"We had made our retirement plans and they just weren't working out the way we had hoped," Leonard said.

Because of their ages, Leonard and Jan had Medicare Part A coverage for hospital expenses, but their private plan was their primary coverage. Unsure of their options, they concluded that purchasing additional Medicare coverage would have cost them more than the escalating costs of their private plan.

The changes in his policy and seeming lack of affordable options left Leonard feeling powerless.

"My concern, if I were to describe it in a nutshell, is the ever-tightening noose and not having some semblance of control," he said. "They [his former employer] say, 'We're going to give you this coverage this year but we're going to cut it next year and we'll cut it some more the following year. So, look forward to that.' What are they really trying to say? When's the next shoe going to drop? That's my point of frustration."

Jan's health issues added to Leonard's concerns. In addition to having type 2 diabetes, she suffered from sleep apnea and heart disease, for which she was hospitalized for several days in 2003.

The need to pinch pennies affected the couple in other ways. It limited their ability to visit three grandchildren who lived out of state. And it forced them to curtail recreational activities that they once enjoyed.

"My recreation is the television," Jan said. "If I can't afford things, I do without. I'm housebound and don't get out often."

Leonard, who at the time of the interview was in good health, attempted to address the situation by working part-time jobs to help with the health care expenses and by going online to compare notes with other retirees in similar circumstances.

"I've worked in the scientific, technical area all my life," he said. "And when you have a problem you put your mind to it and find a solution. You can't sit in a corner and cry and gnash your teeth. There's a solution out there somewhere."

Policy Note

Many might question if Medicare would be a cheaper option for Leonard and Jan. The couple already has Medicare Part A for hospital care, but, if they decided to cancel their private insurance, they would need to pay $270–$300 a month for outpatient services and prescription drug coverage (i.e., $110 each for outpatient premiums [Part B] and $25–$40 each for prescription drug coverage [Part D]). Medicare recipients often need to purchase a supplemental policy to help pay deductibles, coinsurance and services not covered by Medicare. For example, the policy may cover the $1,100 deductible for hospital stays and the $275–$550 daily coinsurance if hospital care is needed past 60 days.

Many seniors don't adequately plan for their health care costs in retirement. For those that intend to rely on employer-sponsored coverage, unexpected changes in coverage can create financial hardship. The Employee Benefit Research Institute reported that, in 2009, a married couple with employer-sponsored coverage needed $165,000–$256,000 to pay for health care costs in retirement. Without employer-sponsored coverage they needed $268,000–$414,000.

"When they said, 'you need bypass surgery today' you don't stop and ask how much it is. You just say 'fix me.'"

Out-of-Network Care Leads to Debt: John's Story

When John's rural Southeast Kansas doctor determined that the former coach needed heart surgery, he referred him to a colleague in an urban area.

So, John, 55, went for what he anticipated would be a thorough assessment of his condition and a discussion about what kind of procedure he needed and when. The second doctor's conclusion was alarming. John needed immediate bypass surgery. And by immediate, the doctor meant that day.

John didn't hesitate. He consented to the surgery not understanding that because the doctor who would perform it and the hospital where it would be done weren't in the network of providers approved by his insurance policy, not all of the costs of the procedure and follow-up care would be covered.

Looking back, John might have spared himself some significant financial problems if he had asked more questions of his doctor, who may or may not have been able to answer them. But, he said, at the time all he could think about was getting the life-saving surgery.

"When they said, 'you need bypass surgery today,' you don't stop and ask how much it is. You just say 'fix me.'"

John said the costs of the surgery, hospitalization and outpatient care, on top of $1,000 monthly co-payments he spent on medications, were more than he could pay. He accumulated stacks of medical bills and insurance paperwork, which his wife, Sarah, helped him to wade through.

"You are constantly watching. Keeping track and paying all the different bills," he said. "Just trying to keep it all straight and the payments up is unbelievably mind boggling, especially for somebody that's sick. There's no way I could have managed if I had been single."

John and Sarah made paying medical bills their top priority, even deciding to live with a leaky roof for four years rather than divert money from paying down their debt. They set up payment plans with willing providers. But they worried that the debt might prove to be too much for them to handle.

"The biggest thing is sitting there worrying about all the bills, the impact it has on your whole life," John said. "If you have a conscience you want to pay your bills. I've always paid my bills and when you can't pay them, it causes you a tremendous amount of worry."

Eventually, some providers turned the couple's outstanding debts over to collection agencies. Remembering it as a "miserable" time, John said the mounting pressures affected both his physical and mental health. His blood pressure shot up and he became depressed.

"There's no question that stress and worry caused a lot of the blood pressure problems and, consequently, probably some of the heart problems," he said. "I'm sure it was a large contributing factor to the depression."

Believing they had exhausted other options, the couple filed for bankruptcy in 2005. Three years later, John qualified for Social Security disability, which also made him eligible for Medicare.

John said the change in coverage led to improvements in his finances because Medicare covered more of the costs of the care he needed than his private plan had.

"We're not accumulating any more medical debt now," John said at the time of the interview. "It's taken us a couple of years but we're going to get [the bills] all paid."

Policy Note

Most managed care organizations contract with providers, defining them as in-network. Health Maintenance Organizations (HMOs) traditionally limit their enrollees to receiving care from in-network providers. Preferred Provider Organizations (PPOs) generally allow enrollees to see any provider but usually have different coinsurance rates between in-network and out-of-network providers. Point-of-Service (POS) plans primarily require enrollees to use a primary care doctor for a referral to a specialist. Almost all health insurance plans place the responsibility of knowing whether a provider is in-network on the insured.

Many people are unclear about which type of insurance they have and often assume that their doctor would only refer them to an in-network provider. Although the responsibility of confirming a provider's status rests with the patient, some, like John, may not think about it when facing a serious medical complication.

National health reform includes some consumer protection standards that might reduce this type of confusion. It also treats out-of-pocket limits equally between in-network and out-of-network providers.

"Every time someone gets sick, I have to ask, 'Does this warrant a doctor's visit?'"

Insured, but with Limitations: Darren's Story

Darren was a frugal health care consumer. He had to be.

The high-deductible policy that he purchased through his employer insured him against catastrophic health events but provided limited coverage for preventative care and basic health care services.

When interviewed, Darren, 37, said that his insurance limited both him and his wife, Olivia, to three covered visits to the doctor per year. And the policy required a $30 co-payment for each of those visits.

Darren's employer, a small organization, paid for his coverage, but not Olivia's $400 monthly premium. The couple purchased an individual high-deductible policy for their three-year-old son, Dustin, after concluding that its $90-per-month cost was cheaper than adding him to their plan.

To avoid exceeding the limits of their policies, Darren said the couple made health care decisions on a case-by-case basis. For instance, he said they decided to forego annual physicals to save their covered visits for serious health needs that might arise. Using the same reasoning, they decided not to take their son, Dustin, in for "well-child visits," check-ups done at recommended intervals to ensure that a child is growing and developing normally.

"Every time I get a call at work from my wife saying our son is sick, I have to think about if he should go in or not because we only have a few of these [office visits]," Darren said. "So, we can't or shouldn't expend them all. I resent going through that process. Every time someone gets sick, I have to ask, 'Does this warrant a doctor's visit?'"

High-deductible plans are designed to influence health care purchasing decisions and potentially lower costs. But go-

ing without regular care can be risky and potentially expensive. Foregoing routine physicals can increase the chances that a serious illness isn't diagnosed early, when it might be easier and less costly to treat.

"It's kind of an irony," Darren said, explaining that despite having coverage, he, like uninsured individuals, was left to wonder about his health and worry about what would happen if he developed an illness that required regular office visits and treatments.

Darren had positive things to say about the doctors and nurses he and his family depended on for care, noting that the providers seemed to have adapted their practice to accommodate people with coverage limits similar to his.

"We can always call and at least talk to a nurse, which is nice," he said. "They do a lot of over-the-phone counseling; as much as they can. They do a good job of taking care of us. So, I think the industry has adapted to the current climate."

And despite his policy's limitations, Darren said that having coverage paid off when he injured himself in a bicycle accident and was taken to the emergency room. His policy covered much of the cost for the visit and the hospital worked out a plan so that he could make payments on the $1,000 in out-of-pocket costs that his policy didn't cover.

But at the time of the interview, Darren had a new challenge. Facing a steep increase in the cost of the coverage offered by his employer, he was searching for a more affordable alternative and worrying about what he would do if he couldn't find one.

"I grew up in an upper-middle-class family," he said. "I always thought that these things happen to other people; that other people don't have insurance or enough insurance. It's shocking when it happens to you."

Policy Note

In 2007–2008, approximately 18 percent of adults under age 65 with private health insurance were enrolled in a high-deductible health plan (HDHP), according to the National Health Interview Survey. Some plans also offer a health savings account (HSA) so individuals can save tax-deferred funds for out-of-pocket medical expenses. In 2010, the minimum deductible for HDHPs with HSAs is $1,200 for an individual and $2,400 for a family. These plans also have maximum out-of-pocket limits of $5,950 for an individual and $11,900 for a family.

HDHPs can encourage people to be more selective about their use of medical services. Like Darren, some individuals face difficult choices about seeking medical care. Recent studies found that adults under age 65 enrolled in HDHPs, with or without HSAs, were more likely to report unmet medical needs due to cost than those enrolled in a traditional plan. Research conducted by The Commonwealth Fund found that these individuals were also more likely to have medical debt, especially when they are sicker.

"You lay there and are up all night long thinking, 'What am I going to do?...I never thought I'd be filing bankruptcy.'"

When Disease Strikes Unexpectedly: Marie's Story

The problems started for Marie and Jim in 2006. That was the year that Jim was diagnosed with a type of Muscular Dystrophy that strikes adults. The tests needed to make the diagnosis and the ensuing experimentation with different drugs to determine which were the most effective in treating the disease proved to be costly processes.

And though the couple and their 7-year-old son, Sean, were covered by health insurance that Marie purchased through her employer, they were required by their policy to pay a portion of the costs of Jim's tests and treatment.

"We had tons of bills pouring in and tons of prescription drugs because they were trying things," Marie, 37, said, explaining that Jim sometimes purchased drugs that the doctors discontinued after a few days because they didn't work.

"So, you have to try something else and you're throwing out a lot of money because doctors don't always have free samples that you can try for a couple of weeks to know if [the medication] will work or not," she said.

Jim's condition worsened. In 2007 he developed vision problems. The next year, suffering from both Muscular Dystrophy and type 2 diabetes, he became unable to work and qualified for Social Security disability and Medicare. The couple enrolled Jim in Medicare and purchased a supplemental policy, not because it was cheaper than private coverage but because it didn't impose a lifetime benefit cap. That was important because people with progressive diseases — like Jim — often have lifetime health care expenses that exceed such caps.

But with only Marie working, the couple struggled to make ends meet.

"My husband's medical expenses take 80 percent of his Social Security income…to pay for his premiums, medical care, prescriptions and the assistive technology he requires," she said.

The couple was paying just under $500 a month in premiums for Jim's Medicare coverage, the policy that Marie purchased through her employer and a single policy for Sean. But that cost combined with payments they were making on existing debts and out-of-pocket expenses for Jim's treatments exceeded their ability to pay. So, they cut back on other expenses.

"We've done without," Marie said. "You don't get new shoes. You don't get new clothes. You don't get new glasses. Work around our house needs to be done but we can't afford to get it done. So, you have an asset that you can't take care of that will no longer be an asset."

And like others with medical debt, the couple bought cheaper, less healthy food and sometimes delayed getting the medical care and services that they needed to avoid the costs.

"You just go without dental care and you go without things like getting new ankle or foot orthotics that you need," Marie said. "Even with a $25 [physician] office co-pay you're thinking, 'I don't want to spend that $25 because it will mean we'll not have gas for next week.'"

Marie's stress grew along with the debt.

"You lay there and are up all night long thinking, 'What am I going to do? How am I going to do it? Are we going to file for bankruptcy? I never thought I'd be filing bankruptcy. I can't believe we're filing bankruptcy,'" Marie said. "Those kinds of thoughts and the stress definitely affect your health."

The couple's efforts to manage their debt by negotiating payment plans with providers, cutting their budget, seeking help from family members and foregoing care worked for a while. But last year when providers started turning their accounts over to collection agencies, Jim and Marie filed for bankruptcy.

At the time of the interview, Marie was grateful for the temporary relief from financial pressures. But she acknowledged that the couple's income would likely not be sufficient to cover Jim's continuing medical expenses.

Policy Note

Like Marie and Jim, most people believe that health insurance protects them from the financial burden of unexpected illness. However, chronic and debilitating illness can result in the accumulation of high medical costs and most insurance policies have lifetime maximums.

A 2009 study showed that 55 percent of individuals covered through employer-sponsored insurance are subject to lifetime maximums. Even a policy through the Kansas High Risk Pool has a lifetime limit of $2,000,000. Federal health reform now prohibits policies from having lifetime maximums.

To avoid the problem of lifetime maximums, Jim enrolled in Medicare, which is often a safety net for people eligible for Social Security disability insurance (SSDI). However, after someone is eligible for SSDI, there is a waiting period before the individual qualifies for Medicare. For many, the waiting period results in the accumulation of medical debt.

"I continue to put medical care on credit cards because I fear they [providers] will deny me treatment."

Credit Card Debt from Health Costs: Valerie's Story

Valerie didn't think much about the adequacy of her health insurance until she developed back pain at age 55.

After a series of diagnostic tests and doctors' visits confirmed that she was suffering from degenerative disc disease, Valerie opted for chiropractic treatments and physical therapy rather than surgery. But, she said, she was surprised when the bills started to arrive for the portion of the office visits, tests and procedures that weren't covered by her insurance.

"I really had no clue," Valerie said. "I really had no idea how much it would cost. When I first started getting the bills and they were in the hundreds of dollars, I thought, 'What do people do that have absolutely no insurance coverage?'"

Valerie was planning to retire at the time that her back pain started. She considered, but decided against, postponing those plans, believing that her condition would improve and that work may have been contributing to her physical problems. Plus, she wanted to use the lump-sum payment she was due to receive from unused sick and vacation days to pay some medical bills that had already started to pile up.

In retirement, Valerie's health care costs continued to stretch her budget. Although she retained the insurance coverage she had through her job, Valerie was responsible for paying the full monthly premium, a 60 percent increase from what she was paying while employed.

Five months into her retirement, Valerie's health care expenses increased again when her health insurance stopped covering her physical therapy and chiropractic care. Even though her medical providers deemed the services medically necessary, the health insurance company argued that Valerie's degenerative

disc disease was a continuing incident that no longer warranted care. This situation forced her to decide between her finances and her health care needs.

"I had no idea what I would do. I felt my only option was to deplete my financial resources until I felt better and could return to work [after retirement]," she said.

The choices became even tougher when her insurance company reduced the amount it covered for physician visits by half. Since Valerie had already used her savings to pay off other medical bills, she started using her credit card to pay for health care services.

"I continue to put medical care on credit cards because I fear they [providers] will deny me treatment," she said. "I want to keep them paid."

Wanting to maintain her treatments but facing mounting credit card debt, Valerie went back to work. Gradually, she started to feel better.

As her condition improved, Valerie said she was tempted to skip an appointment here and there to keep her debt manageable. But fearing a return of the pain, she made continuing her monthly visits to the doctor her "highest priority."

"When I'm feeling better, as I have for several months now, the temptation is to say I probably don't need to do that [go for an appointment]," she said. "But I know I do and my family has been very helpful in reminding me of how much pain I was in before."

The improvements in Valerie's health came at a price. At the time of the interview she had $20,000 in health-care-only credit card debt and was worried about whether the increasing balances would soon force her to start cutting back on care.

"Does everybody have to make these choices about treatment?" she asked. "Is everybody experiencing these kinds of bills with co-pays and deductibles even with good insurance? When somebody is running upwards of a thousand dollars a month in credit card bills in order to pay for their out-of-pocket expenses for health care, that person needs assistance."

Policy Note

Valerie is like many people who pay for medical care on credit cards. A 2006 study, *Borrowing to Stay Healthy: How Credit Card Debt is Related to Medical Expenses*, found that of the 1,150 low- and middle-income households interviewed, 29 percent reported medical expenses contributed to their credit card debt. The average credit card debt for these individuals was $11,623 compared to the $7,964 average for those that did not indicate that medical expenses contributed to their debt. For those with medical debt, having insurance only decreased the average debt amount by $97.

Individuals using credit cards to pay off medical debt can face problems with poor credit ratings and growing interest rates. In March 2010, the average consumer credit card interest rate was approximately 17 percent. The ongoing need for medical treatment, coupled with high interest rates, often makes it challenging for people with chronic conditions to get out of debt.

"I simply can't afford all the MRI's, it's just really expensive for me."

When Debt Delays a Diagnosis: Sam's Story

Sam was a successful business executive until a neurological disorder put his career on hold.

The disorder, which in addition to seizures and muscle contractions sometimes caused him to lose consciousness, made him unable to hold a full-time job and to continue as his family's primary bread winner.

A few years after the symptoms of his neurological disorder appeared, Sam, who was 60 at the time of the interview, also developed heart problems and type 2 diabetes.

Unable to work, Sam and his wife, Rachel, were forced to depend on her salary alone. It quickly became apparent that it wasn't sufficient to cover both their household expenses and his mounting health care costs.

Even though Sam described the health insurance that the couple purchased through Rachel's employer as "relatively good," it, like many policies, required them to pay a portion of Sam's ongoing medical costs in addition to the monthly premium.

Unable to keep up with the deductibles and co-payments, the couple soon found themselves in debt.

"Everything is relative," Sam explained. "The $3,000 out-of-pocket [expenses] would normally be nothing, but when you don't have a position [job] it becomes insurmountable. We pretty much subsist on my wife's income. I just can't pay my medical bills. It's tough, very tough."

The mounting debt affected more than the couple's finances. It also influenced decisions Sam made about his care. He discontinued mental health counseling and started selectively filling prescriptions.

"I had to triage my medications," he said. "I decided to treat the things that would kill me the quickest, such as my diabetes."

Cost concerns also prevented Sam from getting answers about his neurological disorder. Faced with conflicting opinions, he hoped that additional tests might lead to a more definitive diagnosis.

But he said he couldn't go back and get the tests until he "caught up" with payments that he owed to providers.

"I simply can't afford all the MRI's, it's just really expensive for me," Sam explained.

One hospital even declined to release the results of tests that had already been done until Sam paid the portion of their cost not covered by his insurance.

Eventually, many of the providers turned Sam's unpaid accounts over to collection agencies. The former business executive said, "I understand why they've done what they've done, yet they don't understand why I can't pay even the smallest amounts."

Sam said the stress of not knowing what was causing his neurological symptoms and his continuing inability to work contributed to his health problems.

"The stress is just so gawd-awful on the entire body, your immune system, your psychology, the way the brain works, your heart. It just worsens everything," he said.

Sam thought that he might be able to go back to work if he could somehow get a definitive diagnosis and treatment for his neurological disorder. But at the time of the interview, he didn't have much hope of that happening. The barriers seemed insurmountable.

"There are a lot of good people on both the provider side and the insurance side," he said. "It's just that we've got a gawd-awful, dysfunctional system that's chewing up lots and lots of good people, including me."

Policy Note

Sam described the stress many experience when facing an undiagnosed neurological condition. The National Institute of Neurological Disorders and Stroke reports that, just a century ago, the only way to achieve a positive diagnosis for many neurological disorders was to perform an autopsy. Now doctors have at least 24 diagnostic tools (e.g., ultrasounds, MRIs and EEGs). A 2006 Office of Inspector General report illustrates the growth in the use of some of these tools. It reports, for every 1,000 Kansans, 128 advanced imaging services (i.e., CT Scans, MRIs and PET scans) were provided in 2005, a 341 percent increase from 1995.

Advanced technology can bring increased costs, and cost-sharing for these services can be significant. For example, MRIs can cost between $400 and $3,500. A health plan that requires 20 percent coinsurance would make a policyholder's responsibility for this test alone between $80 and $700. Multiple tests can easily result in medical debt. However, like Sam, many Kansans might not know that providers cannot withhold medical records, including test results, due to medical debt.

"I pay a monthly premium for nothing really because I still have to pay for all my insulin and doctor visits."

A Pre-existing Condition Restriction: Bob's Story

Bob is one of the 18 million diabetics in the United States.

He has type 1 diabetes, an autoimmune disease that strikes children, adolescents and young adults causing the pancreas to stop producing insulin, a hormone that the body requires to convert food to energy. It's a lifelong illness that, even if managed carefully, can lead to kidney failure, blindness, heart attacks, strokes and early death.

When interviewed, Bob, 40, had just stopped working for a Kansas City, Kan., business that didn't offer health insurance. While employed there, he purchased an individual policy for $140 a month. Bob's wife, Mary, and daughter, Ashley, have coverage through Mary's employer.

His individual plan provided him with general coverage but it excluded any expenses related to his diabetes because it was a pre-existing condition. Bob said he thought purchasing the policy was the responsible thing to do, but he wondered about what he was actually getting for his $140 monthly premium.

"I pay a monthly premium for nothing really because I still have to pay for all my insulin and doctor visits," he said. "It only covers anything non-diabetes related, which also worries me because if something did go wrong, they could say it was caused by type 1 diabetes."

Bob's health insurance premium combined with what he paid for uncovered insulin and testing supplies totaled about $440 a month.

"I spend $120 a month on test strips and about $180 on insulin a month. That's a lot of money," Bob said. "My mortgage is only $560."

When including the cost of Bob's quarterly physician office visits, his monthly expenses were still less than what it would have cost for Bob to join Mary's plan.

To make ends meet, Bob purchased his diabetic testing supplies online at reduced prices, put home repairs on hold and decided that his family would have to go without many of the amenities that other families take for granted.

"We shut off the phones, shut off the cable service, shut of the Internet," he said. "Everything we could cut out, we cut out."

They also started limiting activities that connected them to social supports, interactions that can be particularly helpful during tough times. For instance, they decided that they couldn't afford to take trips to visit friends and family because of high gasoline prices.

Despite their frugal lifestyle, Bob and Mary were forced to depend on their parents and grandparents for financial support.

"They're actually the reason we've been able to make it," Bob said, explaining that in addition to money, the couple's parents and grandparents sometimes took them out to eat and helped with clothes.

"My wife's mom and dad bought my shoes that I've got on today and my jeans," Bob said.

Food was another issue. The couple's need to stretch their grocery dollars as far as possible sometimes made it difficult to make healthy choices.

"We want to get the right kind of food," Bob said. "You can buy cheap pastas and things but it's not good for you. It certainly isn't good for someone with type 1 diabetes because pastas are full of carbohydrates. The healthiest food is expensive."

For Bob, the stress of managing his disease was intensified by having to also juggle the family's limited finances.

Several years ago Bob owed $30,000 in medical debt that he couldn't pay. So, he filed for bankruptcy and the financial pressures eased for a while. But at the time of the interview, his debts were growing again because of his inability to keep up with his monthly medical expenses.

The pressure Bob felt over the debt and the sleepless nights it caused put his already fragile health at greater risk.

"With type 1 diabetes, my life expectancy isn't much past 65 and retirement for me is 67," he said. "I'm likely not going to make it."

But for Bob, there were a few bright spots on the horizon at the time of the interview. Bob said he had started a new job and was looking forward to purchasing health insurance from his new employer. Although he was going to have to wait three months to enroll, he was grateful that his new, more comprehensive policy would cover expenses related to his diabetes.

Policy Note

Bob is like many Kansans that have been denied coverage of a pre-existing condition. In Kansas, an insurer can deny coverage for pre-existing conditions for 90 days in the small and large group markets, depending on the individual's previous health insurance coverage. A plan in the large group market (51 or more employees) can deny coverage for a pre-existing condition treated in the past three months and a plan in the small group market (2–50 employees) can deny coverage for a pre-existing condition treated in the past six months.

Bob had an individual plan. In Kansas, individual plans allow denial of coverage for pre-existing conditions for two years and allows the exclusion of all coverage for a specific condition for the life of a policy.

Federal health reform, effective six months after passing the law, prohibits insurance plans from denying children coverage for pre-existing conditions. In 2014, this prohibition will extend to adults.

"I had waited for months for an answer and all the while my functional level went downhill."

Insurance Denies, Patient Pays: Karen's Story

Karen's limp was noticeable. Still, she carried herself with confidence.

The 55-year-old researcher had used a prosthetic right leg since she had a below-the-knee amputation at age 11, but had maintained an active lifestyle.

Two years prior to being interviewed, Karen suffered an injury while working in her barn that fractured her right knee. Doctors told her they couldn't surgically repair the damaged joint and recommended extending her amputation to above the knee, which meant that the prosthetic leg she had at the time would no longer fit.

Knowing what a new prosthesis costs, Karen checked her insurance plan to make sure the expense would be covered before authorizing surgery. It seemed to limit payments for prosthetics, so she called for clarification. She was informed there was an error in the contract language and that the payment cap did not apply to prosthetics.

After being assured that her insurance would cover a new leg, Karen proceeded with the amputation.

"When the [benefits] cap was removed, I was enormously relieved," Karen said. "I've always been an incredibly active person and I didn't want to lose my mobility."

After her surgery, Karen received a temporary prosthesis to use while the swelling subsided. A temporary prosthesis is typically only worn for a few months to help an individual stay mobile and learn to walk. But Karen was forced to use hers for many months while she waited for her insurance to approve the permanent prosthesis her physician had prescribed.

As she waited, the temporary prosthesis became more and more unstable and difficult to use.

"I had waited for months for an answer and all the while my functional level went downhill," she said. "I lost what I gained when…I was learning to walk again and undergoing physical therapy. My therapist suggested we stop because the risk of injury increased due to the temporary prosthesis being so ill-fitting."

Not having a permanent prosthesis also affected Karen's ability to do her job.

"I fell twice in one week," she recalled. "I had to ask other people to do the physical part of my job."

Since part of Karen's research involved working with infants, the instability of the temporary leg became a work hazard.

After waiting six months for approval, Karen decided to withdraw $30,000 from her retirement savings to personally pay for the permanent prosthesis. She said her decision was prompted by growing concerns about her health and the safety issues at work.

"I was absolutely exhausted, which was [the insurance company's] goal, to wear me out until I just gave up," she said. "Finally, when I realized my health was in the balance, for my own health and to protect my mental and physical well-being, I bought the prosthesis myself."

Karen had hoped that insurance would reimburse her for this expense. Her appeals were denied. The insurance company paid twice for procedures that Karen needed to ensure that the permanent prosthesis fit properly, but it continued to refuse to cover the cost of the leg itself because it featured an electronic knee component that they classified as more than a basic prosthesis.

"Of course it [the leg] wouldn't work without those parts, like a car without a motor or a pacemaker without a battery," Karen said. "The knee technology had been out for 10 years so it wasn't something new and fancy. All of our service men and women use it and it's covered by Medicaid and Medicare."

Even though she had to purchase it herself, Karen said having the appropriate prosthesis immediately improved her mobility. But she said the physical limitations she developed from using the temporary leg had set back her recovery.

The delay affected more than Karen's physical recovery. It also affected her mental health. She said the physical and emotional difficulties and the back-and-forth with the insurance company made her feel like "this pathetic creature out begging for a leg with a tin cup."

Policy Note

Karen works for an employer that is self-insured. A self-insured plan is when an employer holds all the financial risk, collects premiums and puts those funds in a pool to pay for medical expenses. The employer might contract with an insurance company to manage the administrative aspects of the plan; therefore, employees may not realize that they are a part of a self-insured plan.

Many insurance policies, like Karen's, cover certain medical services or equipment while denying others. Federal health reform calls for four tiers of comprehensive coverage. However, it is unclear to what extent even comprehensive coverage would ensure payment for certain types of medical equipment. Even if the new law requires coverage for the medical equipment Karen needed, it is likely that many of the provisions in federal health reform will not apply to self-insured health plans like Karen's.

Conclusion

These stories from everyday Kansans speak for themselves. And while each individual story is significant, it is also important to view the stories collectively. Together, they illustrate the multiple dimensions of underinsurance and the underlying impact insurance limitations have on individuals.

Most of the Kansans interviewed experienced financial strains due to underinsurance. For some, multiple out-of-pocket expenses or high-cost treatments for unexpected illness or injury contributed to medical debt. To manage this debt, these individuals reported that they transferred it to credit cards, developed payment plans, withdrew funds from retirement savings or took second jobs to pay the bills. Even with these efforts, four out of the ten people interviewed filed bankruptcy due to their medical debt.

The financial impact of underinsurance affected these individuals in other ways as well. For example, many explained that they cut back on social activities, ignored needed home repairs, purchased cheaper but less health foods or delayed needed medical care.

Most of the Kansans interviewed reported social, emotional and medical consequences of being underinsured. Some revealed that the stress of medical debt impacted their marriage and relationships with other family members. Others talked about experiencing depression, increased blood pressure or how stress or lack of treatment aggravated their illness.

The impact of underinsurance can reach beyond the individual to places of employment. As illustrated in these stories, some people experienced decreased productivity at work due to untreated medical conditions, stress or having to deal with collection agency calls. Others had to quit work because of their medical conditions.

Federal health reform, more formally called the Patient Protection and Affordable Care Act, may address some of the issues raised in these stories. Health reform has many provisions that are intended to increase access and decrease cost of health insurance. These provisions include, but are not limited to, the following: guaranteeing access to insurance; eliminating pre-existing condition restrictions; providing premium credits; giving free choice vouchers; and developing insurance exchanges. Health reform also has provisions that limit out-of-pocket expenses, provide subsidies, eliminate lifetime maximums and provide comprehensive benefit requirements for plans in the exchanges.

Although federal health reform seems to address many of the components of underinsurance, it has some limitations. For example, several provisions only apply to the exchanges, new plans or the individual and small group markets. Others, like premium credits and cost-sharing subsidies, only apply to individuals within a certain income range. Although the new law will limit out-of-pocket expenses for some, these expenses still can be as high as $11,900 for a family.

While some provisions in health reform address the challenges illustrated in these stories, the Kansans interviewed may not see immediate relief. Although the provision of eliminating lifetime maximums goes into effect immediately, other provisions won't be effective until 2014. Federal health reform also doesn't provide relief for medical debt already accumulated.

These known limitations suggest that health reform will not comprehensively resolve the problem of underinsurance, leaving the subject an ongoing challenge for policymakers at both the state and national levels.

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