



Heartache in the Heartland

KANSANS SPEAK ABOUT THE BURDEN OF MEDICAL DEBT

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The Access Project (TAP) has served as a resource center for local communities working to improve health and healthcare access since 1998. The mission of The Access Project is to strengthen community action, promote social change, and improve health, especially for those who are most vulnerable. TAP conducts community action research in conjunction with local leaders to improve the quality of relevant information needed to change the health system. The Access Project's fiscal sponsor is Third Sector New England, a non-profit with more than 40 years of experience in public and community health projects. TAP is affiliated with the Heller School for Social Policy and Management at Brandeis University.

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The Kansas Health Consumer Coalition (KHCC) was launched in 2004. Its mission is to advocate for affordable, accessible, and quality health care for every person in Kansas; it hopes to strengthen the voice of Kansans on critical health care issues. The early impetus for the development of this group began in May 2001, when Anthem Health Plans filed its intention to assume ownership of Blue Cross and Blue Shield of Kansas. This action galvanized local health care advocates to form an opposition to this takeover effort. Advocates were mobilized against this issue because they believed that a takeover could mean a dramatic and worsening change in the state's health care system. Consumers turned out to public meetings and continually let their voices be heard throughout the process. This energy demonstrated the power a group of knowledgeable consumers can have to influence health system change.

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Introduction

Over the past year, there has been growing scrutiny of medical debt—money owed to health care providers or other lenders for medical services—as more and more people discovered that their health insurance didn't necessarily protect them from financial troubles caused by medical expenses. These bills can ruin a person's credit for many years and have a strong influence on the financial well-being of families and, by extension, communities. They can also seriously hinder access to health care.

In early February, researchers from Harvard's Medical and Law Schools released a report in the journal *Health Affairs* entitled "Illness and Injury as Contributors to Bankruptcy."¹ It got enormous attention all around the country. An editorial in the March 4, 2005 *Boston Globe* cited the study's main findings:

It concluded that between 46.2% and 54.5% of all filings could be traced back to serious medical problems. In many cases, the illness or injury forced a family breadwinner to stop work. In other cases, it was the cost of care that overwhelmed families. One surprising finding was that three-quarters of those bankrupted by illness had health insurance when the illness first struck. Many lost it after the illness forced them to stop working. In other cases, the health insurance policies' co-payments, deductibles, and uncovered services left the families with medication and treatment costs that were beyond their means.

The Access Project, a national research and advocacy center that supports local groups working to expand access to care for uninsured and underserved populations, has received funding from the United Methodist Health Ministry Fund and the W.K. Kellogg Foundation to research the scope and consequences of medical debt for people in Kansas. The focus group described in this study aimed to gain insight into the experiences and perceptions of a small sampling of adults with significant amounts of accumulated medical debt. Our aim was to put a face on the experience of medical debt—to take a "sounding," if you will.

At the suggestion of the Kansas Association for the Medically Underserved (KAMU), we conducted the focus group in Emporia, which is a city of 26,000 residents in eastern Kansas. It is located in Lyon County, 93 miles northeast of Wichita, the largest city in the state (population 344,000); and 55 miles southwest of the capital Topeka, (population 122,000). The uninsurance rate for residents under age 65 in that region of the state was estimated at 12.8% (14.3% of adults and 9.8% of children lack coverage).²

¹ Himmelstein D, Warren E, Thorne D, Woolhandler S. "MarketWatch: Illness And Injury As Contributors To Bankruptcy", *Health Affairs*, Feb. 2, 2005.

² Kansas Insurance Department, HRSA State Planning Grant, *Finding and Filling the Gaps: Developing a Strategic Plan to Cover all Kansans*, Follow-up report to the Secretary, Sept. 28, 2001– March 1, 2002.

Methods

Focus group research is especially well-suited for exploring sensitive topics that have been previously under-researched. The dynamics and synergy of the group setting can elicit information that would likely not be forthcoming in a one-on-one interview.^{3, 4}

On February 9, 2005, five women, between the ages of 25 and 47, who had been recruited through a social worker at the Lyon County Health Department, participated in a 90 minute discussion. The Flint Hills Community Health Center hosted the discussion with a dinner before hand. Full recordings of the session were transcribed and analyzed. We were especially interested in determining the barriers to health care that may result from having inadequate insurance and exploring the sources and consequences of unpaid medical bills.

Findings

Putting a face on people with medical debt. We changed the names to protect the anonymity of the participants.

Emily

Emily has a large family (seven children from combined marriages). Both she and her husband have health insurance through their jobs and all the children are covered. Her husband was in a farm accident, her 3 year-old developed asthma, pneumonia and a heart condition, and she has a newborn. Collectively, the accident, two emergency room visits and the bills surrounding her newborn are the primary

“Healthcare is not-it’s not something like you just went out and bought a diamond ring and something you don’t need...and they treat you as if you did it as cosmetic surgery or whatever.”

causes of her medical debt. Her insurance has high premiums and deductibles. As the bills mounted, the hospital would not work with her to develop a payment plan so some bills could not be paid on time and were sent to collection agencies. Because of owing money, she does not seek medical

treatment and much needed exams, and lives with her health problems in order to have enough money for the family budget. Her 3 year-old daughter requires special tests that Emily must weigh on the basis of whether or not the doctor says it is a life-threatening situation because she and her husband cannot afford the medical expense. Another consequence of her medical expenses is often not having money to pay for her children’s school lunches.

³ Mofidi M, Rozier RG, and King RS. “Problems with access to dental care for Medicaid-insured children: What Caregivers Think.” *Am J Public Health*, 2002; 92.

⁴ Carey M. “The group effect on focus groups: planning, implementing, and interpreting focus group research.” In: Morse J, ed. *Critical Issues in Qualitative Research Methods*, Thousand Oaks, CA: Sage Publications; 1994.

She has strong opinions concerning the way in which medical debt is being perceived in the United States:

Healthcare is not—it's not something like you just went out and bought a diamond ring and something you don't need. This is something you need. And they treat you as if you did it as cosmetic surgery or whatever.

Maria

While living in Texas in her early twenties, Maria was diagnosed with Crohn's disease and had surgery—two colon resections—while she was covered by insurance. She moved to Emporia with her family four months ago to attend nursing school. When she first arrived, she was employed for two weeks before

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going into a Crohn's crisis that put her in the hospital. She lost her job. She is currently a student, but due to the condition of her health, she is not able to work. Maria has been in and out of the hospital three times; bills for a one-week stay in the

hospital amounted to \$19,000. She has been denied disability benefits and SRS, but has received donations from faith-based charities in order to pay for her medicines. She has to go to the emergency room to receive needed medicines, including steroids. She cannot afford to see a specialist. She has relied heavily on the Lyon County Health Department in order to receive medications and some care. Maria is worried about the debt she has accumulated:

I know my hospital bills at home, plus here, are about \$65,000. And that just kind of worries me. I'm only 25 years old, and I know my Crohn's will never go away, so you know, they keep adding up, and I don't know what—I mean, there's nothing that I can do. You know, I can't give them something I don't have.

Maria's estimated medical debt (TX & KS): \$65,000

Pamela

Pamela is a registered nurse. She and her family have health insurance through her husband's employer. Her medical debt accumulated from health conditions affecting her two sons and herself. Her younger son has 80% hearing loss, which led to a misdiagnosis of autism. Her older son has a potentially fatal gastroenteritis disorder similar to Crohn's disease. Her sons' medications average \$300 per month and last year totaled \$8,000. The cost of hearing aids varies. She was overcharged for one pair of hearing aids, but with help from the Jones Foundation, got the erroneous bill adjusted from \$7,000 to \$2,500. Pamela's health conditions began with stomachaches, which were originally misdiagnosed as panic attacks. She has

had a hysterectomy and gallbladder removed. She was misdiagnosed repeatedly and developed heart disease from medication she was prescribed, leading to stage 2 of heart failure. Pamela is currently undergoing a battery of further tests to determine her complete diagnosis. Although her husband has insurance, not everything is covered, deductibles are very high and co-payments to numerous specialists have added up. In 2004, they paid \$12,000 in out-of-pocket expenses.

She worked double shifts and her husband taught an extra class to try to pay all of their medical costs. Due to her medical conditions, her family and physicians urged her to quit working. She is now unemployed and her family is a one-income household. In their attempt to pay all of the bills, they have liquidated all of the assets that they could, including withdrawing hardship payments from different savings and retirement benefits. They have also taken a second mortgage on their home. They have begun seeking assistance, but make too much money for reduced or free school lunches for their children. Occasionally, they have to go without groceries. The medical debt her family experiences, coupled with her illnesses, has led her to a constant feeling of isolation and severe depression. Her children have also begun showing signs and symptoms of depression. Pamela, once proud to work in health care as an RN, now has no desire to ever work in health care again and is disgusted by the poor quality of care she has experienced.

Pamela's estimated medical debt: \$10,000-20,000

Barbara

Barbara works with disabled adults. She stated that most of her past employers did not offer health insurance. Ironically, even when she worked as an insurance agent,

"[My] credit won't ever be cleaned up...and that causes you more stress, and that causes you illness, and you just go round and round with it."

she was never offered health insurance as an employee. She was, however, covered while she was in the Naval Reserve, but got out 10 years ago. Barbara was working building diesel engines at the time she discovered she had

breast cancer. She had been placed in the job by a temp agency that failed to submit the insurance paperwork after her 90 day waiting period was up, so although she was eligible for coverage, she did not receive it. Barbara had to have surgery, chemotherapy, and radiation treatments. Because of the medical bills, legal action was taken against her by health care providers and her wages were garnished.

As a divorced, single mother of two children, her ex-husband's insurance was supposed to cover their minor children. He now lives in another part of the state and unfortunately, his insurance policy did not cover doctors in the Emporia catchments area. She thought her children's medical bills were being covered but her ex-husband never sent her the bills or communicated with the health care

providers. The medical bills continued to add up for both herself and for her children.

As her bills mounted, she finally had to voluntarily go to court in order to give up residential custody of her 17 year-old daughter because she could not afford to support her. Her medical debt led to her filing for bankruptcy, which has stained her credit. Because of this bad credit, she cannot obtain employment in the areas in which she specializes. She has developed severe neuralgia in both arms and cannot afford her pain medications or her hormonal medication. She relies heavily on the Health Department for care and medications. Barbara mentioned that because she has not been cancer-free for 10 years, if she were offered health insurance, the policy would cost more than \$400 a month. Barbara described the stress related to bad credit:

[My] credit won't ever be cleaned up. You turn around and you're scared to get the mail, because here's another thing going, credit bureau, you know? I got one today and I was scared to open it. I knew it was from an attorney... And that causes you more stress, and that causes you illness, and you just go round and round with it. But it was a release of a garnishment, because I don't work at that place anymore. But I'm just waiting for the next one to come.

Barbara's estimated medical debt: \$90,000

Sharon

Sharon has had serious, multiple health problems over the last seven years, including diabetes, pancreatitis, congestive heart failure and asthma (requiring her to be on oxygen). She is in her mid-thirties. She was employed with insurance at the time of her first illness but had to miss a lot of work. She was fired and lost her health insurance coverage. She applied for Medicaid, but made \$60 a month too much, due to veterans' benefits she was receiving after her ex-husband's death. Since then, she has had intermittent public insurance coverage. She had a partial hysterectomy, and two years later, gall bladder surgery. She has had surgery for her pancreas, and three surgeries for an enlarged hernia. Sharon reported that because she could not afford to go back to the surgeon, she removed her own staples from her stomach after one of the hernia operations. Doctors could not perform surgery on a subsequent hernia until she lost weight, but insulin and other health conditions made losing weight difficult. Her operation could not be done without gastric bypass surgery, which was considered cosmetic by the insurance coverage she had at the time. She finally was referred to a doctor who would do gastric banding and the hernia operation at the same time, but the cost was \$11,000. A faith-based organization raised the money she needed to have the operation. In addition to her own health condition, her 12-year-old daughter needs various medications for her Attention Deficit Disorder.

Sharon has been sued by hospitals and collections agencies because she has no money to pay her medical bills. In one instance, she was very ill and could not make

"And you tell them, you know, you can't get blood out of a turnip."

her court appearance, and a bench warrant was issued for her arrest (she was to appear because of a medical bill). In another instance, while attempting to get approved for Medicaid, she was told by a judge that

she was lazy and overweight and did not want to work. She relies heavily on the Health Department for services and maintenance care. She has recently been approved for Medicaid, but because of the need for frequent hospital visits due to her chronic conditions, the co-payments are still beyond her budget. Sharon spoke about the constant calls from creditors:

From November until I had surgery, I was in from five to ten days every month, with pancreatitis. ... And I get calls from creditors 10 to 20 times every day, on their little recorded messages. "This is KCI. Please call me at this number by 5:00." And if I don't call them back, and they know that I can't afford to pay them, they just keep sending the recordings. And you tell them, you know, you can't get blood out of a turnip. I mean, you pay \$10 to this one, \$10 to this one, \$10 to this one, and you have 30 of them, you know, and I live on \$1,200 a month.

She also made it clear that she was not looking for a government handout:

.... I heard things like, "What -- do you want the government to take care of you?" You know, and I'm not asking for a hand-out. I don't want welfare ... I just need a little bit of help to get going again.

Sharon's estimated medical debt: \$60,000

Delaying Care. The fact that people without health insurance delay care until their conditions worsen is well documented.^{5, 6, 7, 8} Researchers are just beginning to explore the prevalence of delayed care for those individuals with medical debt, whether they have insurance coverage or are uninsured. While the focus group

⁵ Hadley J. "Sicker and poorer—The consequences of being uninsured: A review of the research on the relationship between health insurance, medical care use, health, work, and income," *Medical Care Research and Review*, 2003, 60 (2 Suppl.): 3S-75S.

⁶ Leatherman S and McCarthy D. *Quality of Health Care in the United States: A Chartbook*. The Commonwealth Fund, April 2002.

⁷ Schoen C and DesRoches CM. "Role of Insurance in Providing Access to Care," *Health Services Research* 35, 3 (April 2000).

⁸ Schoen C and DesRoches CM. "Uninsured and Unstably Insured: The Importance of Continuous Insurance Coverage," *Health Services Research*, April 2000, Part II.

participants' testimony cannot quantify the rate of occurrence of this behavior, it can certainly contextualize why people postpone going for more care when their bills have already demoralized them.

I know that I do put off a lot of my tests because, you know, you can't afford them. You know you're supposed to go and get scoped and

"I know that I do put off a lot of my tests because, you know, you can't afford them."

different stuff, and they've told me twice that they've thought I have colon cancer and just different stuff like that,

and if you can't do it, you can't do it. And you know, like with my medicines, if I'm in pain, and I have a doctor that's telling me, well, I'm not giving you no more pain medicine, or I can't afford it. I'm taking Tylenol, taking Tylenol, and then I'm in the emergency room and my liver enzymes are high. ... I know I do put off a lot of stuff because I can't afford it.

I know I need to go in for some other medical care and other things that are major issues, but I just live with certain things, just because of the high deductibles and everything else, and just hoping each day at a time that we'll be all right. But

you keep putting off some things, and keep putting off because of all the tests you've been through in some areas, and different things, and not wanting to go

"...you know really if you go through some of those tests then it only means surgery and more bills."

through them again because you know really if you go through some of those tests then it only means surgery and more bills, and more things. And it's like, it's already too high. I already don't have enough money to pay what we already have, so just letting some things go, even though I have insurance, because it's not there.

"...All I want to say is, start listening to people...there have been many times I deferred going to the doctor because I can't afford the \$20 co-pay."

I don't want to file a lawsuit against them. All I want to say is, start listening to people. I just don't want anyone to hurt the way that I have seen people hurt. And yes, you know, there have been

many times I deferred going to the doctor because I can't afford the \$20 co-pay. And I just would rather stay at home and vomit, and hurt so bad that I want to die.

Like my three-year-old has had heart conditions and gets checked every year with different things. ... But there are other things with her growth, and other concerns with her being so small, ... and other kind of tests and things that have been mentioned that, well, we should do this and we probably should do this. And we're holding off, not trying to keep from hurting her or anything, but asking the pediatricians, like, well, can we just wait? I mean, it's not life-threatening or whatever? Yes, but maybe you'll need to know like in a year or so if these are major issues with your child, and different things. And I mean, then if you start getting diagnosed, having certain diagnoses come through, will they end up being insured or not, eventually, if they start getting labeled on some things? Those are scary factors as well, for pre-existing conditions.

Common themes within the group. The stories of the focus group participants illustrate that medical debt can be devastating and that it can occur among people with health insurance coverage.

Illness can lead to loss of health insurance

Illness can lead to a cascading of problems. People lose their employer-based insurance coverage because of illness and an inability to work. Most of the participants in this study had health insurance coverage early in the course of treating the family's health care needs. Illness and missed work resulted in the loss of a job. For the focus group participants, the loss of income made it virtually impossible to maintain their health insurance coverage. Unfortunately, the health care needs continued long after the insurance coverage was terminated. This was a common occurrence in a recent Harvard University report. "Often illness led to job loss and with it the loss of health insurance."⁹

Chronic health needs can outstrip health insurance protection

Families with chronic health care needs can find their health care expenses to be crushing. Several participants experienced chronic illness. Again, their ongoing health care needs resulted in high levels of medical debt. This is consistent with various research studies, for example one done by the Center for Studying Health System Change that found a significant number of Americans afflicted with a chronic condition had problems paying medical bills:

For the 6.6 million uninsured, chronically ill Americans, the financial consequences are especially grave—nearly half reported medical bill problems, making them much more likely to forgo or delay needed medical care. Among the 3 million uninsured, chronically ill people

⁹ Himmelstein D, Warren E, Thorne D, Woolhandler S. "MarketWatch: Illness And Injury As Contributors To Bankruptcy," *Health Affairs*, Feb. 2, 2005.

*with medical bill problems, four in 10 went without needed care, two in three put off care and seven in 10 did not fill a prescription in the past year because of cost concerns.*¹⁰

Medical bills can exhaust family savings

Illness and medical bills can destroy the American dream. Participants attempted to pay their medical bills but found the level of debt beyond their ability to pay. Participants took second jobs, liquidated assets, exhausted savings and retirement accounts and also took out second mortgages on their homes in order to pay their bills. Recent national surveys have had similar findings. In the Commonwealth Fund's Biennial Health Insurance Survey in 2003, 44% of adults (between the ages of 19 and 64) with medical bill problems or accrued medical debt used all or most of their savings on their medical bills.¹¹

Health insurance can fail to protect families from crushing debt

All participants had insurance coverage at some point in time during their bouts with illness. It is striking that even participants with continuous coverage were not shielded from medical debts. Families with insurance, especially those with chronic or ongoing health care needs, are responsible for paying significant costs out of their own pockets. It is often not until people begin accessing care that they discover that not all services are covered or that the deductibles can be very high and unaffordable.

Medical debt can serve as a barrier to future medical services

All participants spoke of the struggle to pay for basic human needs while attempting to pay off outstanding medical bills. Many were concerned that the outstanding bills would have a detrimental effect on their relationship with care providers. As a result, they were forced to weigh the trade off of delayed treatment so as to avoid additional medical bills. Other studies have revealed that chronically ill people with medical bill problems go without or delay needed care and do not fill prescriptions because of cost concerns.¹²

Safety net providers can mitigate access problems for people with medical debt

Participants from this group relied heavily on the Lyon County Health Department and Flint Hills Community Health Clinic for care and medications. Their concerns about incurring additional debt led them to seek care in settings where reduced cost

¹⁰ Tu HT. "Rising health costs, medical debt and chronic conditions." *Center for Studying Health System Change*, Issue Brief No. 88, September 2004.

¹¹ Edwards J. "How Medical Debt Threatens Economic Security and Access to Care." Presentation at Families USA Conference, Jan. 27, 2005. The Commonwealth Fund.

¹² Tu HT. "Rising health costs, medical debt and chronic conditions." *Center for Studying Health System Change*, Issue Brief No. 88, September 2004.

care or financial assistance was clearly available to them. In spite of long waits to be seen, participants also utilized the emergency departments of the two local hospitals or the emergency department in Kansas City in order to receive needed medications.

Suggestions and concerns raised by the group. The focus group participants were pleased to be invited to suggest remedies or solutions to the billing practices now in place. The following were among their suggestions:

- There should be some type of sliding billing scale for both services rendered and for insurance policies.
- There needs to be some type of temporary disability care program available for those who need to receive treatments or surgery causing them to be without employment for a period of time.
- There should be more restrictions placed on insurance agencies, not allowing them to determine what medical services are covered and what are not.

Concerns expressed by the participants included:

- A common fear was that it is nearly impossible to find coverage or change providers if you have a “pre-existing” condition. Most of our participants had experienced and believe they will experience in the future a prejudice based on their pre-existing conditions. Therefore, the long-term impact is one that never allows them to overcome their debt.
- Although only one woman in the group had been taken to court for non-payment of her medical bills, others shared a concern with the fact that the legal system in Kansas and other parts of the United States allow individuals to be arrested with bench warrants due to failure to appear in court for medical debt while being incapacitated due to illness.
- Flaws in doctor-patient communication were raised throughout the discussion. The perceived lack of listening ability among medical care providers leads to poor quality of care, misdiagnosis, excessive medical tests and exams, which also leads to increased medical expenses and debt. Doctors and physicians need to take into consideration that with access to vast amounts of information, patients may actually know what they are talking about, and be able to understand research.

The stories that these five women shared on February 9, 2005 need to be heard and amplified. Focus group research is not considered generalizable. We did not attempt to select participants on a random basis, but rather sought out people on the basis of their having information-rich cases that we could explore with them. Following the focus group, they all expressed willingness to speak to the press about their individual situations. Please contact the authors if you would like to interview any of these women.

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