

VOICES OF THE UNINSURED: KANSANS TELL THEIR STORIES AND OFFER SOLUTIONS

Barbara L. Smith, Ph.D., M.H.S.A., R.N.
Eldonna Sylvia, M.N., A.R.N.P.
Principal Investigators



Commissioned by: Kansas Insurance Department

Prepared by:
University of Kansas Medical Center
School of Nursing
School of Medicine
School of Allied Health



Supported by a grant from the Health Resources and Services Administration,
U.S. Department of Health and Human Services

CONTENTS

Acknowledgements	2
Executive Summary	3
Introduction	5
About the Study	5
Sample Description	6
Demographics	6
Socioeconomic	6
Access to Health Insurance	6
Six Stories of Uninsured Kansans	7
Bill	8
Jeanne and Larry	10
Denise	11
Beth	13
Juanita	15
Donna and Jack	16
Uninsured Kansans' Experiences and Views On What Affects Their Insurance Status	18
A Mythical Safety Net	19
Gamble With Health	20
Make a Health Deal	21
Casualty of the System	22
What Are Solutions to Reducing the Uninsured?	24
Support the Working Poor	24
Create Value So We Can Contribute	25
Beyond the Insurance Solution	26
Summary	27
APPENDIX A. Study Methods	28
APPENDIX B. Map of Study Regions	31
APPENDIX C. Interview Guides	32

Acknowledgments

This type of research is highly personal and very dependent on the willingness of participants to critically and thoughtfully respond to challenging questions, often about their private affairs. And because the meanings achieved from each interview are unique, each is essential to fully understand the phenomenon in question. Only with the collaborative effort and significant contribution from study participants could we, as a research team, have achieved the depth and quality of work we believe this report provides.

First and primary it is important to acknowledge the 50 individuals and families that helped us to understand what it is like to need and seek health care when uninsured. This was no easy matter. They were asked to invite someone they didn't know into their homes, submit to questions about very personal issues, and formulate careful reasoned responses concerning a very complex issue, all without monetary reward. Each did all of this and more, with a graciousness and sense of responsibility that underscores their recognition of the significance of this issue, not just for themselves but other less fortunate Kansans. All Kansans owe them a debt of gratitude.

Second, we wish to acknowledge the community health care providers and administrators and other community individuals that assisted us in making contact with uninsured individuals and families. Along with referral assistance several providers and administrators participated in an interview, sharing their experiences and knowledge about the uninsured. All of these individuals displayed an obvious attention to the needs of the study and consideration of their community's unique issues, putting aside their own day-to-day concerns to search for the larger picture. Their contributions were invaluable.

Executive Summary

This study explored the personal experiences of uninsured Kansans in an effort to develop a comprehensive picture of factors affecting their uninsured status and their ideas for solving the uninsured problem in Kansas. The data came from in-depth interviews of 57 uninsured individuals from 50 Kansas households, representing various employment status (unemployed, part-time, full-time), race/ethnicity groups, i.e. Hispanic and African-American, and county population density (urban, rural, frontier). The age range of participants was 19-63 years. The majority of participants were female and most were employed (88%), typically at part-time (58%) low wage jobs.

Key Findings

Factors Affecting Uninsured Status

Uninsured Kansans recognized health insurance was important for their welfare and were generally willing to pay for insurance that was affordable. Yet the following factors affected their ability to become insured:

- The presence of a ***mythical safety net***, which, in reality, had many gaping holes in regard to accessible and affordable insurance and adequate health care. The more individuals experienced the limitations of the failsafe system, often because of medical problems, the more they realized and experienced these gaping holes. Continued interaction with this inadequate safety net resulted in significant personal distress for the uninsured as well as diminished resources and inability to obtain insurance.
- Uninsured individuals found themselves forced into ***gambling with their health*** or trying to find health care or insurance bargains, ***making a health deal***, when confronted with the mythical safety net. These actions only postponed and often worsened the uninsured individual's situation but were the only choices they saw available in the face of potential financial and medical disaster.
- That many of the uninsured became ***casualties of the system*** as they gambled with their health or looked for deals, trying to make the best of the mythical safety net. Burdened by health care related debt, unable to hold on to jobs with livable wages due to poorly treated medical problems, and further refusal from both public and private insurers to access health insurance, left many in personal and financial disaster and completely uninsurable.

Solutions to the Uninsured Problem

Uninsured Kansans believed that changing uninsured status would require mechanisms that supported their desire to contribute and assisted them in reaching as close to a level playing field with the insured as possible. Broad methods suggested that would assist in achieving these overall goals included:

- Solutions that supported or invested in uninsured individuals' desire to work or ***support the working poor***. Not only did the uninsured have an economic self-interest in

maintaining employment, many believed the state of Kansas and employers should have similar interests.

Recommended ways to “support the working poor” included efforts to:

- ◆ Expand employers health benefits to all employees, even part-time and helping businesses, in particular small employers, provide affordable insurance through such methods as tax incentives or pooling employer groups;
 - ◆ Expand public insurance to the working poor, particularly working parents; and
 - ◆ Provide interim insurance to those who are temporarily disabled.
- Mechanisms that create an insurance product with value so that uninsured individuals can afford to contribute, or *create value so we can contribute*. Uninsured individuals believed they could contribute approximately \$50 to \$86 a month for insurance if the premium cost was based on their income and the insurance product covered the majority of health costs.

Recommended ways to create an insurance product of value included:

- ◆ Modernizing Medicaid so that enrollment is less intrusive and complex and is disconnected from the welfare stigma;
 - ◆ Developing a statewide pool of commercial insurers that would provide a group rate for the individual; and
 - ◆ Subsidizing insurance cost above a defined income-based contribution.
- Solutions that went *beyond insurance*, including expansion of support to safety net clinics, equalizing discounts for health care services, and education on finding and purchasing health insurance.

Introduction

This study, supported by a grant from the Health Resources and Services Administration, U.S. Department of Health and Human Services, to the Kansas Insurance Department, was one of three research components designed to provide comprehensive data to policymakers on the non-elderly uninsured in Kansas. The research team included health services researchers from Schools of Nursing, Medicine, and Allied Health at the University of Kansas Medical Center. This qualitative study component was undertaken to understand views of uninsured Kansans on: (1) factors affecting their uninsured status and (2) solutions that would expand insurance to more uninsured Kansans.

A third objective of this study component was to understand more fully the experiences of individual Kansans as they addressed health concerns absent health insurance coverage. Through these lived experiences additional insights were provided as to the complexity of issues that affect whether a person can obtain insurance and the many factors that must be addressed to reduce the number of uninsured Kansans.

About the Study

For this study in-depth interviews with 57 uninsured non-elderly Kansans, representing 50 households, were conducted from January 2001 through March 2001. All but a few of the interviews took place in participants' homes. The interviews were semi-structured, using a prepared interview guide. All interviews were audiotaped and were approximately 45 minutes in length. Interviews were conducted in Spanish, as needed, with an interpreter assisting the investigator. Further information about the study method and copies of interview guides can be found in Appendix A and C, respectively.

Study participants were solicited from community contacts, generally health care providers or administrators. An effort was made to interview a diverse sample of uninsured Kansans as possible in relation to ethnicity/racial group, residence county density, and employment status. Adults in 6 of the 50 households were unemployed at the time of the interview; the remaining households had at least one employed adult. Thirteen of the 50 households were non-Caucasian. Interviews were conducted across the state with uninsured individuals living in an array of urban, rural, and frontier counties. Further description of the uninsured participants is provided under Sample Descriptions, p. 6.

A second set of interviews, with 10 groups (18 individuals) of health care providers and administrators, was conducted in April 2001. Participants in these interviews included health care administrators and providers, e.g. nurses, a physician and social workers. Information from these interviews was used to ascertain the accuracy and comprehensiveness of findings from interviews with the uninsured. These interviews were audiotaped and the interview guide contained similar questions as those used with uninsured participants.

Sample Description

Demographics

The sample of uninsured Kansans included 57 individuals in 50 households, including 7 married couples participating in the household interviews. The age range of those interviewed was 19-63 with a mean age of 42.7 years. Of the 57 participants 76% were female and 24% were male. Six (12%) of the uninsured individuals interviewed were African-American and 7 (14%) were Hispanic. The uninsured participants' residences were located in 25 Kansas counties, 3 (12%) of which were classified as frontier, 10 (40%) as rural, and 12 (48%) as urban.

Socioeconomic

The sample included a wide variety of household types, e.g. single individuals, married couples with grown children no longer in the home, married couples with children, single parents, and unmarried couples. At least one adult was employed in 44 of the 50 households (88%).

Using the most fully employed adult to determine household employment status 15 (30%) of households had one adult member who was employed full-time. Conversely, more than half (29 or 58%) of household adults were employed part-time.

Overall the uninsured individuals interviewed described themselves as the “working poor.” Many of the participants indicated that they worked at jobs paying minimum or low wages, e.g. \$7 or \$8 per hour. The most common types of employment indicated by participants were child-care, manual labor, nursing home aide or home companion, cook or food service. Less common employment categories included farmer, teacher, construction, feedlot manager, and truck drivers.

Access to health insurance

This group of uninsured participants was largely chronically uninsured. Of the 50 individuals who were primary interview participants 12 (24%) had been uninsured for more than 10 years, 3 of which had been uninsured more than 20 years. Another 11 (22%) participants had been uninsured for 5 to 10 years.

Only 15 of the 44 (34%) households with an employed adult had health benefits available at work. The remaining 29 households with an employed adult (66%) had no available employer health benefit or the adult was ineligible for the benefit. In 10 of these 29 households the adult was self-employed; adults in the remaining 19 households without employer health benefits worked in small businesses (less than 50 employees).

Six Stories of Uninsured Kansans

What follows are six personal stories of the families and individuals interviewed. Although specific demographic information has been altered to protect individual confidentiality, actual experiences are presented as the uninsured described them. These stories, as told by Bill, Jeanne and Larry, Denise, Beth, Juanita, and Donna and Jack, serve two purposes. First, to understand fully what it is like to be uninsured and worried about or seeking care in our health system, the experiences of uninsured Kansans need to be heard through their words. The stories help to make the experiences of the uninsured Kansans more comprehensible and visible.

A second purpose of these stories is that through reading them one can begin to see the commonalities or themes that cut across the uninsured experience. Bill, Beth, and the four other stories are not presented because they were the most unusual but because they were typical of the uninsured that were interviewed. Finding those broad commonalities between the uninsured participants and organizing the similarities into themes provides a way to say something about uninsured Kansans; what it is like to be uninsured, what are the consequences, and what effects uninsured status. Simply put, the themes developed in this study, which are discussed in detail following the stories, p. 18, assist in describing the views and experiences of uninsured Kansans as a group, essential to making the situations faced by uninsured Kansans fathomable.

Bill

Bill, who is 55 years old, married, with three grown children, lives in an urban area in eastern Kansas. Bill, as he discussed his present situation, emphasized how unexpected the financial and physical dilemmas he now faces were. He explained that, early in his career, he and his wife, both full-time professionals, had easy access to health insurance, "...and of course in those kind of jobs you have benefit packages and you have insurance and she had a job where she had health insurance and so forth. This was not an issue, we had double coverage." Confident with his wife's solid work situation, Bill began his own construction business. The problem developed, he explained, "when my wife reached the point where she could no longer work full-time and we could no longer get those benefits." Pointing out that "in the past I've been able to make really good money," he continued, "We just went along paying our medical bills, essentially hoping nothing catastrophic happened."

What did happen was catastrophic. About three years ago he was diagnosed with diabetes. With this and some business downturns, he and his family, as he explained, "had a tremendous swing in our financial future all in a three to four month period. We went from anticipating prosperity to financial disaster." At the same time he found that he was unable to purchase individual insurance, exacerbating this financial disaster. He explained, "Having been diagnosed as diabetic now securing health insurance was very difficult, the costs were very high if it's available at all." He continued, describing the insurance "gap" that he faced, "If you've got the money to buy it or you're employed some place where they offer it you can have correct coverage. And if you're making almost nothing you can qualify for Medicaid and in between those two is never never land and that's where a lot of us live."

Recounting how he got to this point he readily admitted to being, "a little cocky or lulled in a sense of complacency, because things were going along well, everybody's healthy, everybody's doing fine." As he noted, the "younger you are the more you tend to believe you're bullet proof. When I developed diabetes my first reaction was I was absolutely ticked off. I was angry. How could this possibly happen to me?"

No longer feeling "bulletproof" Bill described his experience with diabetes and his efforts to manage this illness, "I knew something was wrong and I just kept thinking, well it will straighten out." When his symptoms worsened he realized something was "seriously wrong" and decided to see his doctor. She called him that evening telling him he had "full-blown diabetes" and that she wanted him "at my office tomorrow ready to go in the hospital." I, of course, told her I can't afford to go to the hospital," and he didn't.

Without health insurance Bill tried to manage his diabetes with as little medical care as possible. Even after developing foot ulcers, "because I didn't have my blood sugars really under control," Bill still avoided recommended treatment. Discussing this dilemma he stated, "I finally went over to the wound care clinic. That's when I got a bill for \$275 and they needed to see me every week and I'm going, oh my God, I can't do that." Faced with losing his feet Bill finally went to one of the public clinics for the uninsured. He attributes the providers there with saving his life.

Although grateful for the care he received at the clinic he recognized that, without insurance, his health care struggle was unresolved. Contemplating the possibility of future major medical problems and where he would get affordable care he summarized his ultimate fears, "I think that, if you are uninsured and without resources and something major happened, let's say I had a heart attack and they decided I needed a quadruple bypass surgery, I think you die. I don't think

you get it. You think anybody's going to do the surgery knowing that they're not going to get paid? No, I think that's an unrealistic expectation."

Getting to affordable insurance Bill believed would require some type of group purchasing pool for individuals that ignored medical conditions. He reviewed in detail his idea of a "state-wide pool" of commercial insurance providers that would accept the uninsured as their "number came up." Bill also indicated that "an expansion of the Medicaid program where you pay a contribution based on your income" could serve this same purpose. Bill's consideration of a public insurance solution was indicative of how desperate his situation had become. As he admitted, "My father would spin in his grave if I showed up with a Medicaid card."

Even if he did get insurance Bill would continue treatment at the public clinic where he still receives care. He believes that "in terms of diabetic care, they're the best I've seen" and "they are more compassionate" than other physician offices. For now he is beginning to "plan my work as to how I can accomplish or what I can do to continue to make a living, where it has to be on a paved surface where a wheelchair will work."

Jeanne and Larry

Jeanne and Larry, 33 and 34 years old respectively, live in a rural community near a moderate sized city in eastern Kansas. They have two children still at home, a son and a daughter, both of whom are in grade school. At the time of the interview Larry, who works for a concrete company, was laid off for the winter. He joked, “Unfortunately every year that’s my vacation, getting laid off. We can’t afford to do anything.” Jeanne, his wife, works as many hours as possible as a nurse’s aide at a nearby long-term care facility.

Neither one has had health insurance for more than 15 years. Jeanne explained that even when she worked for a local hospital she wasn’t eligible for their benefits because of her part-time status. Although Larry can get insurance at his job it is too expensive. Larry detailed the costs explaining, “I checked it out and it would have been like \$192 a week for family coverage and I make less than \$300 a week. And I think it was pretty much just hospital, from what I gathered. You know the only way it’s really going to pay off is if you went into the hospital.” Jeanne quickly noted the reality of their budget, “You know, it’s like do we pay our mortgage and eat or do we buy insurance?” They feel lucky though because this last year they were able to get HeathWave for their two children.

Jeanne and Larry also feel lucky that the local health department has a clinic where they can go for basic medical care. Recalling how close he was to a life-threatening stroke, Larry described how the nurse at this clinic discovered his carotid artery was “90 percent clogged.” Although grateful to be alive they now have enormous hospital bills, more than “\$10,000 for the hospital and \$5,000 for the surgeon.” Jeanne explained that they are “just paying out of our pocket. \$20 to one, \$30 to another and I get in there every month and I make my payment. And if he’s laid off and I don’t have the money I take them \$10, I take them something.”

These aren’t the only medical bills Jeanne and Larry have accumulated, as Jeanne has a hospital bill from evaluation of abdominal pain. Along with hospital bills there are other regular medical costs. For example, Larry has high blood pressure and takes medication daily. The nurse at the clinic has helped them get free samples from pharmaceutical companies. Although Larry realized the application process required the nurse to complete a lot of monthly paperwork he stated, “If it wasn’t for the free samples we couldn’t afford the medicine.” In fact, during the 12 years he has had high blood pressure he has stopped the medication a number of times because he “couldn’t afford it.” Larry is also trying to get by with his dental problems. Although he’s been told that all his teeth need to be pulled the cost is prohibitive. He explained, “the dentist wants \$85 a tooth unless it has to be surgically extracted, which most of mine have busted off and so every one of them...it will be close to \$300 a piece. Just to pull the teeth in my mouth would cost a couple of grand.”

Larry’s view is that working people have been ignored in regard to public insurance. He complained that the government “lets people sit around and do nothing and collect welfare and Medicaid and it’s working people who, we make too much to qualify for that kind of thing, but not enough to survive.” He continued, explaining that because he doesn’t have much education “I’ve got to take what you call low income jobs. You know, the hardest part is the lower income, if there would be some way to have some guidelines for insurance cost to help the lower income people.” Larry also believes employers “should kick in a certain amount” to help working people. He’s not sure how much the employer contribution should be but he thinks that by contributing employers “give you an incentive.” Right now all Jeanne and Larry know is that “if there was more insurance that was affordable we’d definitely be looking into it.”

Denise

Denise, who is 39 years old and a single parent, lives in a metropolitan area in central Kansas with her 15-year-old son and another son, 19-years-old, who “mostly comes here to do his laundry.” Denise described herself as someone who has “helped people all her life.” Explaining that she has been a Certified Nurse Aide and worked in nursing homes since she was 18 years old, she proudly admitted to her devotion to people she cared for and the importance of helping others, “I don’t really want to do any other work. I love helping people. If I was rich, I’d be poor, because I’d give it all away.”

Denise wondered aloud, though, about who will help her. She has found herself in what she calls a “complete financial slumber” as her medical problems have devastated her income, both because of medical debt and inability to maintain full-time employment. Because of this debt she has had to file medical bankruptcy. Explaining how she got to this point she stated, “I had well over \$40,000 in medical bills. I’ve had to have 14 major surgeries. I’m a single parent; it was like there was nothing I could do. I did take a second job but it was part-time because health-wise I’m working without medication as it was at these jobs.”

Going without her medication, as she is now aware, only worsened her chronic medical conditions, which included diabetes, high blood pressure, and arthritis. But, as she explained, because of medical debt “I’ve tried to be self-sufficient.” She described what it is like to seek care under these financial conditions, “I’ve been embarrassed at the hospitals, telling me if you don’t make a payment we can’t treat you anymore. I had a doctor tell me in the room with another person, ‘We can’t take these poverty cases anymore.’ I’ve been admitted in a mental state, almost having a nervous breakdown being told that in the hospital. So you name it, I’ve been through the embarrassment.” Recently she fell and tore her rotator cuff and injured her leg. Pointing to her leg she exclaimed, “This is what happens to a person who’s scared to go to the hospital. My leg, I almost got gangrene in it. I had no range of motion in my arm. But that’s due to being hurt by how people talk to you when you have no money to pay for medical services.”

Looking back, given “the mess I’m in financially and mentally,” Denise thinks she would have made different decisions about health insurance. “What would I give up now to get insurance? I would have to take another job but I would pay the \$400 a month [for insurance] if I could redo it.” At the time she didn’t feel she could afford her employer’s health benefit, explaining, “How could you afford \$400 a month making \$7 an hour and working 35 hours a week?” Now, because of her arm injury and other medical conditions, she can work only for a temporary agency that provides no health benefits.

Denise has found some assistance along the way. Although she was never eligible for Medicaid, her son was able to get HealthWave. Along with HealthWave she found help for her medical problems from a federally funded safety-net clinic. Describing the assistance this clinic has provided she stated, “They’ve sent me to the hospital on a sliding scale. They will pay for my medication and when I go for my surgery it’s going to be just very minimum pay because I have no money. They’ve been wonderful.”

In considering solutions to the uninsured problem Denise thinks the government should provide more assistance to the safety net clinics, because, in doing so the government would be “helping me and the next person. They would help me as I could still work and if I was working I could give a little more money to the clinic to help the other people.” Most importantly she wants to get back to work and knows she needs some type of temporary assistance, whether it be insurance or the clinic, to do so. Because of her positive experience with HealthWave she wondered

out loud about this type of public insurance for adults, “Whoever came into that organization and got HealthWave going, I want to commend them for that. How about a HealthWave for the middle aged person?”

Whatever the case Denise feels the government needs to give a little back to “hardworking” people. Pleading her case she stated, “if there would be somebody that would be willing to listen in an insurance company to know there’s poor people out here and we do need help. We’re willing to work, we just can’t afford the high prices that they’re saying we have to pay.”

Beth

Beth, who is 29 years old, lives with her husband and two daughters, ages 7 and 3 years, in a rural community in western Kansas. Although as a lab technician she could easily work at the local hospital, she has chosen to stay home with her children. To supplement their income she provides a daycare in her home. Her husband, who is 30, works as a manager in a small meat packing plant. Neither Beth nor her husband have insurance and she doubts that they will be able to afford health insurance until she goes back to work at the hospital. She believes, though, that she and her husband are “very blessed that in this last year we’ve been able to get the two girls on HealthWave.”

Health insurance for her children has not always been available. In fact, when they first moved to western Kansas they were disappointed to find out her husband’s job was not going to provide an employee health benefit. Because they had expected the benefit Beth, who at that time was still working at the hospital, didn’t take up the hospital plan. When she tried to get back on the hospital benefit plan, because it was past the sign up period, the insurance company would not cover her older daughter’s cardiac disorder. Beth and her husband decided not to buy this coverage. As Beth pointed out, “This was a lot of money to pay and the only thing that we used the insurance for was our daughter. If they aren’t going to cover the main thing what do we need it for?”

This sent she and her husband on a search for affordable individual private insurance. Beth described this process, “We applied to I can’t tell you how many insurance companies and they would either put riders on one or both our daughters, even on our newborn,” even though her newborn had no cardiac problem, “because she was a sibling. We even had insurance companies decline my husband who had had a temporary medical problem” with an ulcer. They decided to give up on insurance. She explained, “We were floored. We are a pretty healthy family and we felt like why pay those kinds of premiums if we’re not even going to get coverage.” In addition, they already had monthly payments to make on past medical bills, leaving them no leeway in their budget. Beth pointed out, “Well when you’re already paying \$300 a month medical payments for back bills you can’t come up with another \$400 for insurance, that’s \$700 in a month to come up with for medical expenses.”

Right now she worries about losing her daughters’ HealthWave coverage when they reapply this year because of her daycare income. And, as she and her husband remain uninsured, they just “don’t go to the doctor, period. We just can’t afford it.” To Beth “what’s sad is that working people get less care than those who don’t work and get Medicaid.” To make up for their lack of insurance Beth bargain hunts for inexpensive care. She gave an example, “I did find the local college dental hygienist program. For \$10 they’ll take x-rays and clean your teeth.” In addition Beth has a good relationship with a local physician who will see her children for no cost in an emergency, an important option if her children’s HealthWave coverage is dropped. In considering future medical needs she was optimistic that the local hospital would give them care and “we would just have to make payments as best we could. I don’t know what else to do as there is no other place to go.”

Beth doesn’t think much of insurance companies. Her biggest complaint is that private pay people like she have to pay more for care than people who have insurance and get a discounted rate. She points out, “it’s like a catch-22; I can’t afford a premium but I’m going to pay more at the hospital to begin with.” Beth knows they need to get some type of group insurance and would support assisting small businesses, like where her husband works, in accessing affordable

health insurance, perhaps through a state pool. She noted though, that, “it has to be a decent policy. It can’t be a policy with such a high deductible that it doesn’t do any good either.” Until they have insurance Beth and her husband plan to continue limiting their health care use.

Juanita

Juanita, who is 30, lives in a moderate sized town in western Kansas with her 2 children, who are 4 years and 10 months old. A Mexican immigrant, Juanita has been in the United States for about 1 1/2 years. She came to the United States because her brother, who works at a feedlot, encouraged her to do so. Although she struggles with the many cultural differences between Mexico and the United States she is happy that she made this change. As Juanita explained, “I feel that my situation has improved. Life is better. It’s a better lifestyle for my children.”

Because she is a single parent and, in addition, speaks little English, Juanita has had difficulty finding work. In spite of these barriers she has begun providing childcare in her home for some income and has made every effort to obtain health care for her children. Indeed part of what Juanita feels is better for her children is the health care. She explained the differences, “In Mexico the doctors treat symptoms and recommend home remedies. Here the doctor diagnoses what the problem is and treats it with medication or whatever is needed.”

Juanita worries though about her difficulty understanding and speaking English. For example, her youngest, born in the United States, is missing “3 fingers on one hand and there are no bones in the hand either.” She continued, “when he was born they came into the room and explained why he had this deformity, but there was no interpreter.” Consequently, she really does not understand why this happened. In addition, when she takes her children to the local health clinic, because the one interpreter is seldom available, she questions whether she understands “what the doctor is saying” to her.

Another worry for Juanita is having no money to pay for emergency care if her children became acutely ill. Tearfully describing a recent situation in which her older son had a very high fever, “it went up to 106,” she stated, “I wanted to take him to the emergency room but the thought of having to pay the bill” kept her from doing so. Because it was evening and the clinic was closed Juanita gave him Tylenol and “used cold compresses.” Although the fever eventually came down Juanita pointed out what an “emotional strain” it is, to know “you’ve got to take care of your child but you’ve got to pay for it.” She explained that many Hispanic parents hesitate to use the emergency room, first because of the language barrier, but also “they hesitate because of the cost. There’s going to be some cost involved and they’re going to be responsible.”

Juanita wishes there were some way that “if the need arises” she could take her child to the emergency room and “know that I can get some help financially.” Also she would like the clinic to have more bilingual people to help with interpreting. Nonetheless Juanita is trying to plan for the future. She looks forward to the day she can get a job with a salary that would improve her family’s living situation. When asked about whether she would buy the employer health insurance if available she hesitated, noting, “I would have to ask other people who have the insurance to see if it was good coverage.” She believes she might be “tricked if somebody explained it in English.”

Donna and Jack

Donna and Jack, 46 and 47 years old respectively, live in a large city in central Kansas with their three children, two girls and a boy, ages 13, 12, and 10 years. Donna hasn't worked outside of the home for several years and worries that, because of significant physical problems, she would be unable to manage a job at this point. She wishes she could, though, because her husband's new plumbing business was put on hold due to his recent medical problem. She explained, "last Saturday we took him to the emergency room and found out he's filled with gallstones." Because of this set back they are both concerned about their bills, particularly the gas bill that they haven't been able to pay. As Donna pointed out, "we're always...my husband's always good at paying up on our bills. It really bothers him that we can't pay the gas bill."

Living on very little income is not new for Donna and Jack. Jack has training in plumbing but has never been licensed. Therefore much of his past work has been at "odd jobs or part-time maintenance." It has seemed like they could never get ahead and their hope to start anew with his own business has been severely delayed. Because of low income, Donna and Jack have relied on public assistance where they could. For example, all three of their children have HealthWave. And recently Donna has pursued disability. Told there was no "Medicaid program for adults" Donna hopes that through disability she will have the insurance she needs to "get back on her feet."

Donna knows that "getting back on her feet" will be a struggle as she and Jack have gone without health insurance during most of their marriage. And without insurance Donna has found little help for the medical problems that have plagued her, including a swallowing disorder, "food gets stuck in my esophagus," chronic ear infections with hearing loss, and severe arthritis. She explained her frustrations with seeking care, "I've tried through the health clinic here in town and all we've developed is a bill. I didn't get anywhere really. One doctor claims that my health problem is that old age is creeping up on me." A nurse at the clinic finally told her that "they can't do anything more unless I have a medical card." And, unfortunately, any prescriptions she does get to relieve symptoms, such as earaches, are out of reach financially. As Donna noted, "Then you've got to go to the pharmacy. They wrote one prescription that was over \$100. So I decided not to get it. I can't do that to my family."

Donna's experience with Jack's recent medical problem emphasized her frustration and sense of abandonment by the health system. Trying everything they could to ease Jack's pain, "We tried hot soaks. We tried Roloids. I feared it was his appendix. It wouldn't go away," Donna took him to the hospital emergency room. After a long waiting period the ER staff "wanted to keep him...they would have kept him, but the hospital claimed they didn't have room. Now I don't know. I had a funny feeling it was because we didn't have insurance." Although they have been referred to the local safety net clinic for assistance with Jack's pending surgery, the help may be too little too late, as they now face an enormous emergency room bill.

Donna's sense of abandonment by the health system is, for her, most worrisome because of her children. As she pointed out, "When you've got kids to take care of and you're sick yourself and you don't have any way to get help. My kids depend on me. But if I'm sick there's no way, it's hard." Commenting further she stated, "You know children need their parents. I understand and I'm very happy that they have these health programs for children but parents who are honestly trying to raise their family and work need health insurance."

Donna doesn't want to "live off the government" but seeing no alternative, began a tortur-

ous and probably losing process of applying for disability to get health insurance. She has already been turned down three times. She wishes Medicaid could be expanded to parents who want to work, “because there are people who are trying to earn their own living but can’t afford to pay the prices of insurance.” She could easily agree to pay something if the insurance was subsidized and likes HealthWave. “The insurance card that we’ve got for the kids, they seem to do fairly well for the kids.” In the meantime she worries about “other parents like us, similar to our case that need health care.”

Uninsured Kansans' Experiences and Views on What Affects Their Insurance Status

These stories illustrate the often distressful and very personal saga all of the uninsured participants in this study revealed in their interviews. Although descriptive of each person's individual circumstance, the stories collectively are also representative of commonalities found among all those interviewed. Those commonalities, expressed by uninsured participants, group into four distinct ideas or themes (Figure 1). Central to all the uninsured stories was the idea of a "mythical safety net," both in relation to adequate and available health care as well as accessible and affordable health insurance. The second and third themes, "gamble with health" and "make a health deal," depicted at the top of Figure 1, summarize how the uninsured interacted with this largely flawed health system. The fourth theme, "casualty of the system," displayed at the bottom of Figure 1, represents what happens to the uninsured as their interaction with this mythical health system escalates producing increased personal distress, overwhelming medical bills, and decreased access to health care and insurance. Further explanation of these themes follows.

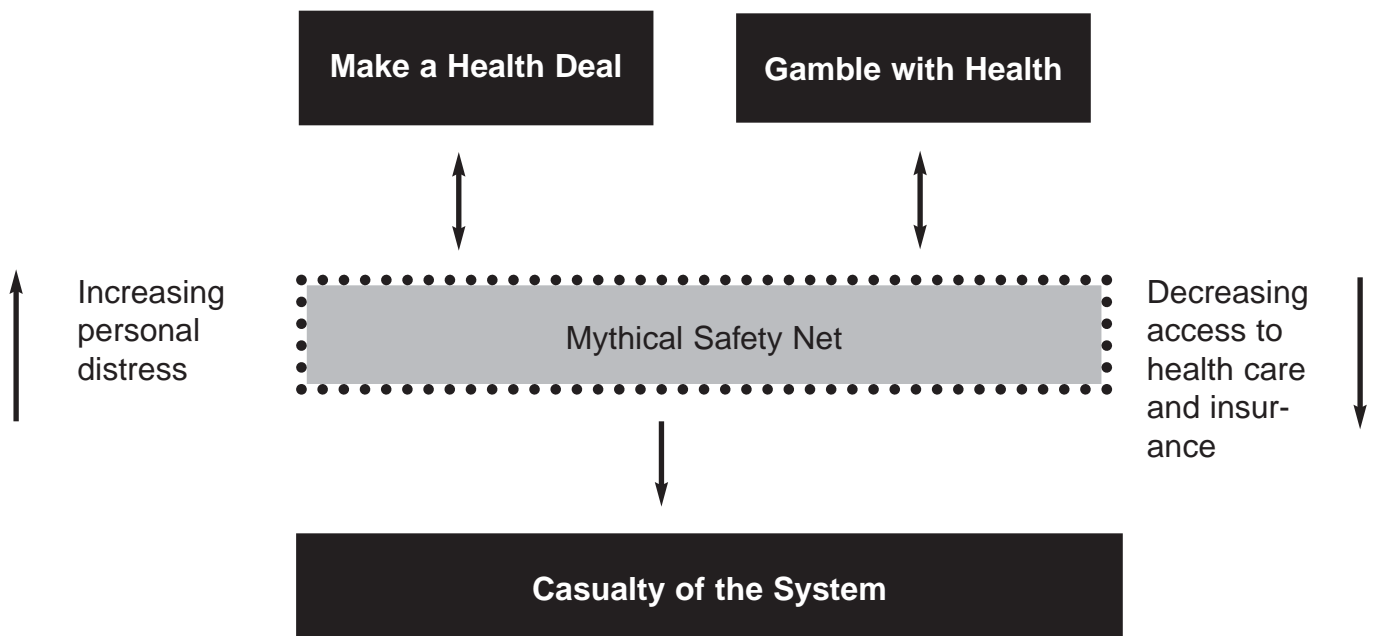


Figure 1. The Factors and Experiences of Being Uninsured in Kansas

A Mythical Safety Net

The first theme, labeled “mythical safety net,” involved two ill-founded beliefs held initially by the uninsured: 1) that there was accessible and affordable health care for the uninsured, and 2) there was insurance for individuals with limited resources. These six stories portray the process that the uninsured experience as they interact with the Kansas health system while trying to access health care and insurance for themselves and their families. What follows is the uninsured participant’s description of each component of this mythical safety net.

A Mythical Health Care Safety Net

The uninsured initially believed that an adequate health care system existed for those with limited resources and no insurance. Few stories could as effectively portray the fallacy of this belief as Denise’s disturbing and eye-opening interaction with a health care provider during a hospitalization. Or Bill, who succinctly confronted the reality of the health care safety net when he articulated his fears that, without insurance and few resources, he just won’t get the care he may need. And Donna, whose story depicts the vicious cycle a person with chronic medical conditions experience when trying to obtain care from a health system that she feels has literally abandoned her.

These six stories also portrayed the patchwork efforts put in place to bolster the absence of a true care system. Safety net clinics, specifically funded through either federal or state dollars to assist uninsured individuals, were one of those patchwork efforts. Bill discussed how important this type of clinic was in practically saving his life. On-the-other-hand Jeanne and Larry’s story depicted the “band aid” aspect of these health clinics, as few provided more than basic primary care, leaving costly specialty and hospital care to the uninsured to resolve. In addition, as in Beth’s case, there was little access to safety net clinics in much of rural Kansas. What Beth hoped was that the local hospital would be there for her. Other health care system efforts, e.g. Larry’s description of the paperwork burdened pharmaceutical program or in Beth’s case, hospital payment plan procedures that only served to spread out enormous health costs, were further examples of this patchwork health care system.

A final element of the mythical health care system, discussed by uninsured participants, was that until illness forced them into direct experience with the safety net, insurance was rationalized as a low priority for already stretched budgets. Bill thought he was “bullet proof,” to health problems and, until he became seriously ill, did not understand the implications of his uninsured status. Denise, after years of experience fighting for needed health care and confronting health costs, in hindsight would buy the insurance that was so unaffordable at the time.

“I’ve been embarrassed at the hospitals, telling me if you don’t make a payment we can’t treat you anymore.”

**Denise, central
Kansas**

A Mythical Insurance Safety Net

The uninsured also found their belief in available health insurance for persons with few resources was false. Before recognizing this insurance myth though, the uninsured, such as Beth, frequently reported attempting an impossible search for health insurance coverage. Bill described this search when he tried to find affordable insurance for himself. Certainly for the growing number of Hispanic immigrants, such as Juanita, differences in language and culture made access to an already complex insurance system nearly impossible.

The myth of accessible public insurance was most frustrating for individuals such as Larry or Beth, who described a system that provided no support to the working poor. Lack of public insurance for poor working adults was also distressful for families with children such as Donna and Jack, highlighting the dichotomy between accessible public insurance for children and inaccessibility for the parents of these children.

The myth of accessible and affordable employer insurance was pointed out over and over again by uninsured interviewees. Of the 44 employed households only about a third (34%) had employer benefits available and all 15 households with benefits described the cost as “unaffordable.” Larry and Denise, for example, explained that if they had purchased their employer’s insurance they would be left with essentially no paycheck. And Beth, after finally realizing her husband’s employer was not going to provide a health insurance benefit, described the overwhelming stress of not having access to employer-based insurance.

Finally, those who pursued purchasing private insurance as individuals described that process as completely “out of the picture” or an “exercise in futility,” both in terms of excessive cost as well as inadequate benefit coverage. Examples of this futility include Beth’s experience as she tried to get coverage for her children or Bill who discovered that because of his now chronic illness he had become essentially uninsurable.

“I’ve checked insurance out at my job and it would have been \$192 a week for family coverage and I make less than \$300 a week.”

Larry, eastern Kansas

Gamble with Health

Faced with a nonexistent health care/health insurance safety net and limited financial resources uninsured participants described being forced to enter a devastating game of chance or “health gamble.” This process involved two types of decisions, either to limit their use of health care services or to forego the purchase of insurance, hoping for continued health. As one health provider explained, “They’re betting on this horse that they’ve seen run for 22 years at a pretty good clip and they’re not seeing that 3 or 4 months down the road they’re going to come up with some diagnosis that’s going to require an ultrasound, which is \$300 or a CAT scan, which is \$800 or whatever.”

Limiting their health care use was a process of “playing the odds on illness.” Many simply hoped their physical problems or symptoms would not worsen or that the problems would be manageable without medical interven-

“I finally went to the wound care clinic. That’s when I got a bill for \$275 and they needed to see me every week and I’m going oh my God, I can’t do that”

Bill, eastern Kansas

tion. For example, Bill, faced with the unaffordable costs of weekly visits to the wound care clinic chose to manage his foot ulcers with much fewer visits. Donna tried all sorts of self-care measures with Jack's severe abdominal pain until his symptoms could no longer be ignored. Juanita, although fearful about her child's fever, chose to provide palliative measures at home rather than assume further emergency room bills. And Larry, faced with the cost of raising a family with low-wage jobs, determined that he could do without his blood pressure medication.

Uninsured interviewees also described "betting on their health" rather than taking up health insurance that did not cover significant medical problems, provided inadequate coverage, or was simply unaffordable within their budget. Not atypical was Beth's decision to forego buying insurance for her "pretty healthy family" because the insurance did not cover her children's health problems. And another uninsured participant highlighted the difficult decision of "betting on your health," when faced with a very limited budget, "When you think you've got, you know, when you've got to pay out money for food and your shelter expense, you just have to take a chance on your health."

Foregoing health insurance was no simple matter. As a health provider participant noted, "I think most people are scared spit-less of being uninsured. They cross their fingers all the time. They get up in the morning and their kid has a fever and they cross their fingers that the fever's going to be gone by the end of the day and it was just a cold. Or they hope that their stomach problem is just a viral infection and it's going to go away and it's not really their gall-bladder. I think that if you would ask any uninsured person on the street whether they would want health insurance or not, I think most people would."

Make a Health Deal

Along with the health gamble, uninsured participants described searching for or "making a deal" for affordable but piecemeal health care or insurance opportunities. Armed with years of experience at finding bargains many of the uninsured participants were highly resourceful at constructing health care or insurance deals; few, though, were able to make any long-term difference in resolving their health care or insurance needs.

Uninsured participants described three methods for deal making to access needed health care services. The first was to monitor and manage their medical payment plans. Attention was focused on strategically postponing payment of hospital or physician bills as long as possible to avoid being cut-off from needed services. A second method for making a health care deal was to "search for bargains." For example, Beth located a low-cost dental hygienist to examine and clean her and her husband's teeth. Others watched for health fairs or found free mammograms. A third deal making method, labeled "provider hop," involved jumping from hospital to hospital or from physician to physician, often because of bad debt, in an attempt to find a physician who would see them.

"His fever went up to 106. I wanted to take him to the emergency room but the thought of having to pay the bill..."

Juanita, western Kansas

"We're just paying out of our pocket. \$20 to one, \$30 to another and I get in there every month and I make my payment. And if he's laid off and I don't have the money I take them \$10, I take them something."

Jeanne, eastern Kansas

Making deals also included a search for affordable insurance. Uninsured participants described two ways for making insurance deals. One was to increase the deductible to a level so that the premium became affordable. A second method, frequently employed by younger individuals, was to buy specialty insurance such as accident or cancer coverage. For example, one interviewee, a young single mother in her 20s, purchased her employer's accident insurance, because her hobby of barrel racing was risky and accident insurance, as opposed to comprehensive health insurance, was affordable.

Casualty of the System

Uninsured participants explained that each encounter with a medical problem forced them to interact with a mythical safety net, thereby increasing the likelihood of their "falling through the holes" and ultimately becoming a "casualty of the system." As "system casualties" many of the uninsured participants described enormous medical debt, poorly treated medical problems, difficulty maintaining their jobs due to poor health, and a downward spiral in their income. In addition, participants who had become casualties described significant distress in their lives as well as a sense of hopelessness at being able to obtain insurance or future health care.

Gambling with health or deal making, the uninsured individuals' methods for trying to obtain needed health care in the face of an inadequate safety net, did not protect them from becoming a casualty. For example, the young woman described earlier who had purchased accident insurance ended up needing surgery because of gallbladder disease. Unfortunately, her accident policy provided no coverage, leaving her a casualty with an overwhelming hospital bill she could not pay.

Uninsured participants spoke about the notion of being a system casualty in two ways. First, uninsured individuals were susceptible to becoming a health care casualty, depicted by Denise and Donna's stories. Denise, drowning in medical debt, represented the 20% of the uninsured participants that had declared medical bankruptcy at least once. Many of these individuals described the same embarrassment or mistreatment as Denise when they sought care or the inaccessibility of care entirely, such in Donna's case.

Interview participants who were health care casualties described a cycle of illness and job loss, resulting in significantly lower income, less access to health care, and a worsening of their medical problems. Bill's description of the enormous change in his financial status once he became acutely diabetic and Denise's explanation of the "complete financial slumber" she experienced were examples of the cycle.

With mounting debt and a worsening of their medical condition, uninsured participants described becoming a second type of system casualty, that of an insurance casualty. As an insurance casualty the uninsured found it increasingly, if not impossible, to access health insurance. Examples of insurance casualties included Denise who, because of medical problems, no longer could work enough to access employer benefits or Bill, because of a chronic

"I had to file medical bankruptcy. I had well over \$40,000 in medical bills. I'm a single parent; there was nothing else I could do. I did take a second job but it was part-time because health-wise I'm working without medication as it was at these jobs."

Denise, central Kansas

illness diagnosis, was unable to purchase private insurance. In addition, medical payment plan costs absorbed income which, in Beth's case further restricting her ability to afford insurance premiums.

Once a system casualty, several uninsured participants described feeling trapped into applying for permanent disability solely to access public health insurance. Their hope, as in Donna's case, was to get needed medical care so that they could return to work. Often a cycle in itself, the process of applying for disability was long and typically required legal action to be successful. In the meantime, physical problems worsened or medical debt increased.

“When you're already paying \$300 a month medical payments for back bills you can't come up with another \$400 for insurance, that's \$700 in a month to come up with for medical expenses.”

**Beth, western
Kansas**

What are Solutions to Reducing the Uninsured?

What do the uninsured see as solutions to improving access to insurance in the face a mythical safety net of health care or insurance? What mechanisms could be put in place to expand insurance to uninsured Kansans, thereby intervening in this cycle of gambling or bargaining for affordable care and insurance? These questions were explored with uninsured participants in an effort to garner their perspective on alternatives to extend health insurance to Kansans. A discussion of the themes generated from these questions follows.

Support the Working Poor

Uninsured participants, who had become system casualties, were not only distressed about their inability to access health care and insurance but that they were no longer considered productive members of society. Few wanted to be considered or labeled as “living off of the government” and most recognized that welfare or disability support provided only a subsistence income. Some participants even recognized the negative economic implications of a system casualty to the state of Kansas - once one is too ill to work you are forced to depend upon government resources, becoming, as one interviewee stated, “a negative on the tax rolls because then you resort to welfare.” Uninsured participants explained that keeping people on the job and/or getting people back to work was essential to preventing “system casualties” and that insurance expansion strategies that “supported the working poor,” the group with which most interviewees identified, were key to this effort.

One consistent recommendation by participants to assist the working poor was that employers provide health insurance benefits for all employees, including those who work part-time. Provision of a health insurance benefit for all employees was considered essential, as most of the interviewees worked in low-wage jobs or for small businesses with no benefits and part-time status was common. Larry, who was a proponent of employer benefits, believed that employer contributions also provided an “incentive” for the employee to pay their portion of the premium.

Methods for helping businesses, particularly small employers access affordable health insurance, were suggested. Example of approaches included Beth’s comments about developing purchasing pools for small employers or the idea, supported by several participants, of providing employer tax incentives based on benefit offerings.

Expanding public insurance to support those doing their best to make a living was another recommendation to help the working poor. Larry, as well as Beth and Donna, advocated public insurance for the working adult, especially working parents.

A last suggestion related to “supporting the working poor” was the rec-

“I think an employer should provide the opportunity and a certain amount towards insurance. It would help a lot of people, say, if you’re going to pay \$20, I’ll pay \$70, cause it gives you incentive.”

Larry, eastern Kansas

“I understand and I’m very happy that they have these health programs for children but parents who are honestly trying to work and raise their family they need health insurance too.”

Donna, central Kansas

ommendation for interim or temporary insurance that would help individuals obtain needed health care so they could return to work. For example, Denise and Donna, both casualties of the system, only wanted temporary assistance so they could “get back on their feet” and go back to work.

Create Value So We Can Contribute

Even though most of the uninsured expressed the belief that they needed insurance, if the insurance did not have value, that is, if the insurance premium was too costly and provided inadequate coverage, the uninsured simply could not afford to purchase the insurance. One key element to insurance value, expressed consistently throughout the interviews, was that insurance cost should be based on a percent of income, a sliding fee that took into account available salary or wage. Second, for insurance to have value, the product would have to limit deductibles and co-pays as well as cover some portion of prescriptions. This limitation on “out of pocket” expenses was essential to making insurance affordable, as once the uninsured bought insurance they had little money left in their budget to pay for health care services.

Two other factors were important to the uninsured in defining a valuable insurance product. First, the insurance must eliminate “pre-existing illness shut-out,” in which the insurer disallowed coverage for any illnesses the individual currently had or had in the past. As Beth’s story demonstrated, the “shut-out” of pre-existing illnesses immediately shifted the value of the insurance product to worthless. Second, although uninsured participants expressed considerable tolerance with past mistreatment from the health care system, there was concern that the insurance product give them equal footing with those who have insurance in obtaining needed health care.

Uninsured interviewees suggested three broad methods for creating value in insurance products. The first of these, labeled “modernize Medicaid,” involved strategies that would make public insurance more palatable or “of value” for the uninsured. One popular method for modernizing Medicaid, suggested by participants, was to create a new public insurance program for adults modeled after HealthWave. Many, such as Denise, saw HealthWave as closer to private insurance than Medicaid, with enrollment less intrusive and complex and separated from the welfare stigma. Reducing the stigma of Medicaid, as insurance for “those who collect welfare,” as Bill suggested, was important in promoting public insurance as an acceptable solution for the uninsured. Modernizing Medicaid, according to participants, also involved creating a mechanism for the uninsured to purchase the insurance, based on income, rather than receiving it free of charge.

Besides modernizing Medicaid many of the uninsured recognized that, individually, they had no power to access an insurance product with value. Bill, for example, who had a chronic uninsurable illness, recommended a statewide pool of commercial insurers that would be required to provide a group rate to individuals regardless of pre-existing illnesses. In addition, Beth knew that until she returned to work at the hospital, where she could access a group rate, her family could not afford to purchase insurance.

“This was a lot of money to pay and the only thing that we used the insurance for was our daughter. If they aren’t going to cover the main thing what do we need it for?”

**Beth, western
Kansas**

“Whoever got HealthWave going, I want to commend them for that. How about a HealthWave for the middle aged person?”

**Denise, central
Kansas**

Third, uninsured participants realized that if insurance payments were based on income, essential to insurance value, the remaining cost would have to be covered. Few had ideas about how to finance such coverage.

Speculating on the availability of an insurance product with value most participants believed individuals should contribute some percent of their income toward the premium cost. Of those that responded to a question about what they could afford to pay monthly (76%) the amount of contribution ranged from \$0 to \$300, an average of about \$50-\$86. None of the interviewees believed insurance should be free; a few admitted that, because of debt, they would be unable to pay anything at this time.

“The solution would be something like a statewide pool for uninsured persons, maybe with a sliding scale. You don’t look at what kind of a health problem you have...”

Bill, eastern Kansas

Beyond the Insurance Solution

Although interview questions focused on solutions to assist individuals in obtaining insurance, participants’ emphasized other recommendations, in particular increased support for safety net clinics. Just as with Bill, Denise, Jeanne and Larry, many uninsured participants were grateful to safety net clinic services, often attributing these services with “saving their lives” as well as being more compassionate and better equipped to assist the uninsured. Equally important, the safety net clinics were considered essential in helping these individuals who would “fall through the cracks.” Denise explained that there would always be individuals who “couldn’t work.” And from Juanita’s standpoint, interpretive services, typically provided only in safety net clinics, were essential for immigrants to effectively negotiate a foreign health system. Commenting on the importance of safety net clinics one provider pointed out limits to increasing access to insurance for vulnerable populations, “I don’t think a subsidy [to purchase employer insurance] would help much below poverty. Because to me that would be like giving a 50% off coupon to the Holiday Inn to the homeless.”

“If I had to make a choice of affording insurance or providing support for the clinics I would go with the clinic because they would be helping me and the next person. A person like me, I can go back to work. There are people that can’t work and can’t afford insurance.”

Denise, central Kansas

Two other issues were considered important by the uninsured as a supplement to insurance solutions. One recommendation, supported by uninsured individuals like Beth, was to equalize the discount for health care services. From Beth’s perspective if she could get the same discount for a surgical procedure as Medicaid she might have a better chance at paying her health care bills. Finally, several of the interviewees expressed a need for educational materials or helpful hints in finding and purchasing health insurance.

Summary

While uninsured Kansans recognized insurance was important for their welfare and expressed a willingness to pay for insurance that was affordable they found themselves instead:

- interacting with a mythical health system that disallowed access to affordable insurance or adequate health care;
- bargaining for affordable health care and insurance as well as gambling with their health in an effort to protect the few resources they had and to obtain care for their health needs; and
- becoming a casualty of the system, unless one of the very lucky few, placing them even further away from affordable health insurance or care.

Solving or intervening in this quagmire of action and reaction, from the perspective of the uninsured, required mechanisms that would support their desire to contribute and assisted them in reaching as close to a level playing field with the insured as possible, including:

- mechanisms that would support the working poor's ability to access insurance such as increasing availability and access to employer health benefits, expanding public insurance to the working poor, and providing interim insurance to those temporarily disabled;
- mechanisms that provided an insurance product with value, that could be purchased based on a percent of income, that covered the majority of health costs and was perceived, both by the uninsured as well as providers, as similar to those products by the general insured population; and
- solutions that promoted and supported equity in health costs as well as access to health care through safety net clinics for all Kansans.

Appendix A

Study Methods

Design and Sample

Qualitative methods with a case-study design were used to achieve the study purpose. The case was the uninsured non-elderly Kansan.

The sampling method was purposive, involving the selection of participants who are expected to be “information rich” because of their experience being uninsured. The sample included 57 individuals from 50 households between the age of 18 and 65 who were without health insurance at the time of the selection. Three criteria were used to maximize variety in the uninsured sample: employment status, whether or not a participant was a member of a minority group, and population density of the participant’s county of residence. Participants were evenly selected within the 10 designated state research regions (Appendix B).

A second sample for interview, called community experts on the uninsured, was obtained to ascertain accuracy and comprehensiveness of findings. This participant sample included health care providers and administrators with experience serving the uninsured.

Data Collection Methods and Procedures

The method of data collection involved semi-structured audiotaped interviews, using prepared interview guides that included specific questions related to the purpose of the study (Appendix C). Although the questions provided structure for the interview they were open-ended to allow for flexibility and in-depth understanding of the participants’ experience and views

Two investigators separately conducted interviews from January 2001 through April 2001. The interview guide was piloted and initial interviews audiotaped and reviewed by both investigators to ensure consistency in overall interviewing technique and to assess understandability and effectiveness of the questions.

Uninsured informants were solicited through communication with key community contacts, most of whom were health care providers or administrators. The community contact was asked to provide 2-3 study participants using the specified criteria of 18 to 65 years old, uninsured, and a variety in employment and minority status. Once the community contact obtained permission participant names and phone numbers were given to the researchers. The researchers then contacted the participant and an agreed upon place and time was arranged for the interview. The majority of the interviews took place in the uninsured participant’s home. Written, informed consent was obtained in advance of the interview. Interviews were about 45 minutes in length and were audiotaped. An interpreter assisted in the interview with those Hispanic participants who did not speak English or who requested to be interviewed in Spanish.

A second group of participants, labeled community experts for the uninsured, were solicited from those community contacts that provided assistance in identifying uninsured participants. The majority of these interviews took place at the community experts’ work site. Written, informed consent was obtained before the interview took place. An interview guide with similar questions as those used in the uninsured individual interviews was used (Appendix C). The interviews were about 45-60 minutes in length and were audiotaped.

Analysis Procedures

The first step involved analysis of the uninsured informant interviews. All interviews were transcribed verbatim. After reading these interviews for a sense of the whole, codes for each new idea were assigned. NUD.ist software was used throughout the analysis to facilitate coding and categorizing of data (Qualitative Solutions and Research NUD.ist, 1994). Definitions of codes were refined through a process of constant comparison among all instances in which the code was used. After interview data was coded, categories were identified to group codes into conceptually linked clusters. Themes were then identified, using metaphors and noting patterns, consistencies, and inconsistencies within certain conditions.

The second analysis step involved the 10 groups of community expert interviews. These interviews were transcribed, coded, and categorized similar to the procedures used for the uninsured interviews. Display of data in matrices was then used to organize and compare similarities and differences in theme elements between the two data sets. Interest, through this different source of information, was in assessing accuracy of themes established from uninsured participant data and adding depth to theme descriptions.

Assurance of Rigor or Trustworthiness

Verification of comprehensiveness and accuracy of findings was achieved through triangulation using two sources of data (the uninsured and health care administrators and providers) and two investigators, as well as standard qualitative techniques to reduce bias and subjectivity. Through triangulation the investigators were able to see if what was observed carried the same meaning when found under different circumstances (investigator) or through different sources. For example, there was considerable support from community expert data in the overall themes generated from the uninsured participants. At the same time data from the community expert interviews highlighted or emphasized theme elements less easily identified within the uninsured informant data, e.g. the addition of stigmatized as an element to the theme “casualty of the system.”

Each investigator maintained a reflective journal to examine bias and other individual issues that emerged during data collection that might impede the effectiveness of this process. In addition, an audit trail of data collection procedure and analysis decisions was maintained to assure a systematic non-bias approach to the study process. Finally, member checks, with three uninsured participants, were conducted to confirm accuracy of findings. Each of the three participants stated that the overall study findings and themes reflected their experiences and were a helpful summary; no changes were suggested.

Limitations

Method limitations included dependence on community contacts to identify uninsured informants, the need to employ an interpreter who was not a member of the research team, and limits in sampling and questions related to ethnic or racial group issues. Because most uninsured participants were identified by health care providers or administrators the sample was somewhat skewed in relation to experience with significant health problems and health care use. In addition it is likely community contacts chose participants with whom they had a positive relationship and who tended to be cooperative with requests. All of these biases may have limited the range and experience of the participants, providing less information about those uninsured who have fewer contacts with health care or have fewer medical problems, and who may have less interest or con-

cern about the lack of health insurance.

A second study limitation had to do with the language and cultural barriers in interviewing the Hispanic participants, a key minority group in relation to the uninsured issue in Kansas. Although effort was made to solicit information from this minority group, including those who were undocumented, dependence upon an interpreter with little research experience and who was uninvolved in the study design limited the depth of understanding achieved in these interviews.

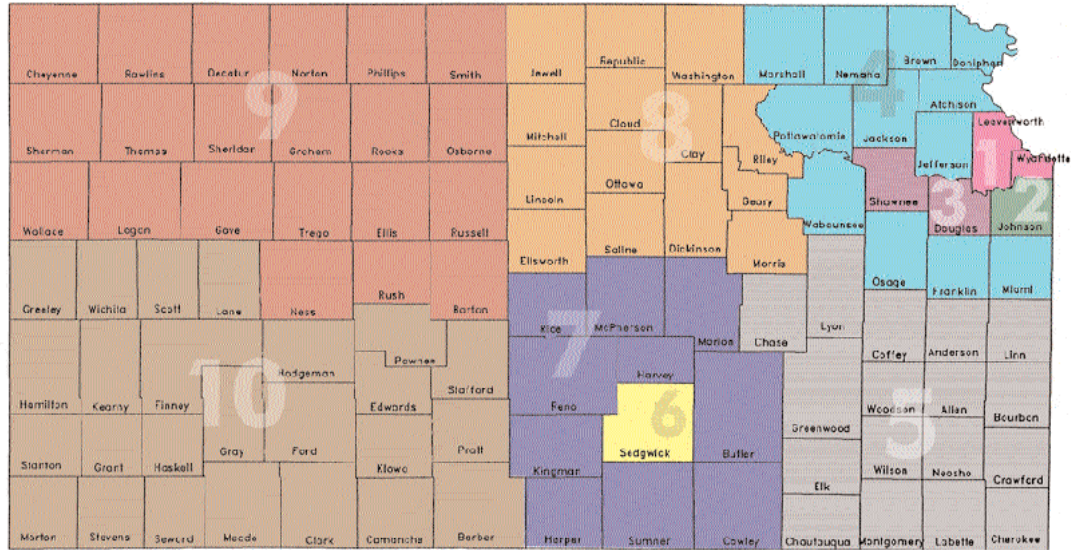
Last, because this study component's objectives were to understand issues related to the uninsured as a whole, sampling and other study methods may have been too broad to adequately capture the complexity of issues facing Kansas uninsured immigrants. In addition, specific immigrant groups, such as those from eastern Asian countries, were absent from the sample, further limiting findings in relation to Kansas immigrants.

Human Subjects

The University of Kansas Medical Center Human Subjects Committee granted approval of this study. Informed consent was obtained from all subjects at the time of the interview. Specific steps were taken to safeguard the confidentiality for all subjects in the study. All subjects were assigned a specific identification number to be used throughout the study. The identification numbers, rather than names, were entered on any transcribed observation notes or interviews. All interview notes, audiotapes, and transcribed interviews were kept in a locked file cabinet in the investigators' office. No identifying information regarding participants was included in any final report. Audiotapes and the list of identification numbers with participant names were destroyed at the completion of the study.

Appendix B

Kansas Survey Districts



Appendix C

Interview Guide

Kansas Uninsured Resident or Resident with Uninsured Dependent

This interview is part of a study of the uninsured in Kansas. We want to know more about your reasons for not having health insurance, either for yourself or a dependent, and your experiences with health care without insurance. We are interested simply in your opinions and experiences. There are no right or wrong answers to the questions I will ask.

1. It would be helpful if you would begin by telling me about yourself, for example describe your present employment, if unemployed what past work you have had, some basic information about your home life, e.g. who you live with, whether you're married or have children, or anything else about your present living situation to help us provide a more complete picture for this study.
2. Switching to the topic of health insurance – I am interviewing you because either you or a dependent does not have health insurance. Please describe that situation in more detail, e.g. how long have you (or dependent) not had health insurance, have you (or dependent) had health insurance in the past, if you had health insurance in the past was it through an employer, Medicaid or Health Wave, or did you buy it individually, etc.
3. This question is about employer health insurance benefits. Tell me about your employer's health insurance benefit, is there a benefit and if so describe what you know about the benefit. (Check if there is a prescription, vision, or dental benefit). If your present employer doesn't provide health benefit do you have experience with past employer health benefits? Please describe. If informant has no experience with employer health benefit skip to #5.
4. You have mentioned that your employer provides health benefits yet you haven't taken the benefit. Describe your reasons for not taking your employer's health benefit, either for you or a dependent. Describe in as much detail as you can what experiences you've had that would help us understand these reasons or what you thought about as you made this decision.

Prompts: Reasons for not getting employer health insurance:

Not eligible for employer health insurance (**Clarify reason**)

Too expensive/can't afford the premium

Don't believe in buying health insurance

Don't need health insurance, as I'm usually healthy

Free or inexpensive care is readily available

Insurance does not cover enough of my health care bills

Probe: You mentioned that you can't afford the premium. What else in your monthly bills/expenses would you have trouble paying if you added the insurance payment?

5. You mentioned your employer doesn't have health benefits or you are self-employed. When this is the case some people have tried to purchase health insurance individually. Describe your experience if you have tried to purchase individual health insurance and your reasons for not buying this type of health insurance. **(Use prompts and probes from #4).**
6. Some people who can't afford health insurance and have children have tried to get Medicaid or HealthWave health insurance. If you have tried to do this for you or a dependent what was your experience?

If you haven't tried describe your reasons for not doing so?

Prompts: Reasons for not getting this type of health insurance:

Don't believe in this type of assistance to pay for health care

These programs are too complicated to try to get enrolled:

I was told I (or my dependent) didn't qualify

Believe I (or my dependent) would not get good care

I didn't know I could get this type of health insurance

7. Switching topics a bit - describe any recent medical problems you (or your dependent) had that you felt a doctor should treat and what you did to take care of this problem.

Prompts for how informant took care of problem:

Didn't do anything because I couldn't afford it

Went to the emergency room of a hospital

Went to the doctor

Obtained free care from a clinic

Made do with non-prescription medicine

If you (or dependent) received care describe that experience, e.g. how you were treated, how you will pay for the care, what has happened with the problem since?

If you (or dependent) were treated for a medical problem in the past when you had health insurance what differences were there, if any, in your experience?

8. What other health concerns do you have for yourself or your dependent? Describe the care you (or dependent) presently get for ____ **(use informant's words for health concern)**. If you had health insurance what differences, if any, do you think there would be in the medical care for ____ **(word for health concern)**?
9. What thoughts do you have about how you would get care or pay for the costs of a major illness or accident?
10. You've talked about difficulties getting health insurance for you or a dependent and worries or problems getting medical care you need without health insurance? What would you say to state government officials about how to fix this?

Prompts: **Help employers offer health insurance by making health insurance more affordable, giving employers tax breaks, etc.**

Require that employers offer health insurance to all employees.

Help people buy their employer's insurance if too costly for them.

Probe: Ask how much informant would pay monthly for employer health insurance.

Let more people like myself buy Medicaid or HealthWave. **Probe: Ask how much informant would pay for this type of insurance.**

Make it more affordable to buy health insurance individually by bringing together groups of similarly employed people to buy insurance.

Expand clinics that offer service to the uninsured that are free or a reduced rate.

11. Is there anything else you would like to add about your experiences with health insurance or best ways to obtain health insurance?

Interview Guide

Community Uninsured Expert

This interview is part of a study of the uninsured in Kansas. We want to know more about the reasons people do not have health insurance, either for themselves or a dependent, what individual's health care is like without insurance, and your ideas about how to reduce the number of uninsured in Kansas. We are interested simply in your opinions and experiences with individuals without health insurance. There are no right or wrong answers to the questions I will ask.

1. Please begin by describing your job or position. In describing your job explain how you come in contact with or have experience with persons who do not have health insurance?
2. From your experience describe what you have found to be a frequent or typical situation for individuals without insurance, e.g. length of time without insurance, any history of having health insurance, and if the individual had health insurance was it through an employer, purchased individually, or government sponsored, e.g. Medicaid?
3. For those individuals who are employed what is your experience with the availability of health benefits for these individuals, e.g., employer doesn't provide health benefits for employees, employer provides benefit but employees not eligible (explain eligibility).
4. Describe what you believe are reasons individuals who are employed and eligible don't purchase their employer's health insurance. **Check if informant believes any of the following are relevant and ask to describe in some detail or give examples:**

Prompts: Reasons people have mentioned include:

Too expensive/can't afford premium

Don't believe in buying health insurance

Don't think they need health insurance, as they are healthy

Free or inexpensive care is readily available

Insurance doesn't pay enough of their medical bills

Probe: You mentioned cost as a reason. In your experience, what effect would paying for insurance benefits have on individuals' budgets?

5. Describe your experience with uninsured persons trying to purchase individual health insurance and reasons for not doing so.
6. As you may know people with lower incomes and children can sometimes get Medicaid or HealthWave. Describe what you think may be reasons individuals do not try to get this type of public health insurance. **Check if informant believes any of the following are relevant – ask to describe in some detail or give examples.**

Prompts:

Don't believe in this type of assistance to pay for health care

These types of programs are too complicated to try to get enrolled

They don't think they qualify

Don't believe they will get good care

They don't know they can get this type of health insurance

7. Describe from your experience how individuals get care for a medical problem they think needs medical care, e.g. where do they go, how do they pay for the care, or if they don't get medical care what do they do about a medical problem? What differences, if any, are there in the care an individual without health insurance might receive from individuals who are insured.

What about differences in on-going management of a medical problem, such as high blood pressure, diabetes, asthma, between these two groups?

8. Again, from your experience with the uninsured, what differences are there, if any, as to the preventive care an uninsured individual obtains from individuals with health insurance?
9. What do you think needs to be done in Kansas to help reduce the number of uninsured? What suggestions do you have for state government officials to fix this problem of the uninsured?

Prompts:

Help employers offer health insurance by making it more affordable for them – **ask informant to describe ideas for doing this, i.e. tax incentives.**

Require all employers to offer health insurance to all employees

Help people buy their employer's health insurance by giving them a subsidy

Increase eligibility for Medicaid and HealthWave

Develop ways to pool group purchasers for people to buy insurance privately

10. Is there anything else you would like to add about reasons persons don't have health insurance or ways to reduce the number of uninsured in Kansas.

