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REFUSAL OF CARE: EVIDENCE FROM ARIZONA

by Bradford L. Kirkman-Liff

Prologue: The effect of medical price competition on the ability of the nation’s poor to attain health care is one of the most passionately discussed issues evolving from the market model. Some researchers and advocates for the poor have postulated that, with the advent of price competition as the allocative instrument in the delivery of care, many people without adequate financial means will be squeezed out of the system. As hospitals and physicians are forced to cut costs, the argument goes, charity care will diminish as providers are forced to become more tough-minded about treating people without insurance or money. Positions taken on this issue, however, have tended to reflect one’s personal opinion, rather than a well-documented study. The following article by Bradford L. Kirkman-Liff, who is an associate professor at Arizona State University, explores the question of whether the poor have been refused access to care under the Arizona Health care Cost Containment System (AHCCCS). Kirkman-Liff, who holds a doctorate in public health from the University of North Carolina, analyzed the issue through a survey on the access to health care for Arizona’s poor, which was conducted by Louis Harris and Associates in the summer of 1984. The survey was underwritten by The Robert Wood Johnson Foundation and the Flinn Foundation. The conclusions reached by Kirkman-Liff are bound to be controversial. AHCCCS enjoys broad political support in Arizona. Lust October, Arizona Gov. Bruce Babbitt spoke out on behalf of AHCCCS while delivering a major address at the annual meeting of the Association of American Medical Colleges. Babbitt declared that several recent studies, one conducted by the Stanford Research Institute for the Health care Financing Administration and another undertaken by the Accreditation Association for Ambulatory Health care, documented that AHCCCS is not only saving money, but also providing quality medical treatment. On the second study, which involved quality-of-care audits of 1,223 medical records at 63 sites, Babbitt said: “The results showed that medical care in our plan fulfills within accepted criteria of practice, and that our patients are being mainstreamed into the general health care system.”
This article explores in depth a major problem in contemporary health policy: the refusals by health care providers to treat the poor. The problem of care refusals is exacerbated by recent trends in the provision of medical care to the poor.\(^1\) The tightening of Medicaid eligibility has made it more difficult for the poor to become eligible for health care assistance.\(^2\) This in turn increases the financial distress faced by traditional providers of care to the poor.\(^3\) At the same time, increasing numbers of the Medicaid population are being enrolled in prepaid, capitated health plans.\(^4\) This approach, with access to care restricted to those providers participating in the program, may result in new barriers to care.

Unfortunately, little is known about the magnitude of the care refusal. While many surveys have assessed the poor’s access to care and satisfaction with care, determination of the frequency with which the poor are refused care has not been attempted in recent research.\(^5\) This is primarily due to the difficulties associated with developing a large random sample of poor individuals, and in turn finding enough cases of care refusal to allow detailed examination of the cases themselves. These methodological problems have made it difficult for policymakers to assess the significance of these occurrences.

Arizona provides a natural laboratory where these trends can be observed. The only state which has foregone participation in Medicaid, Arizona in 1982 launched an experimental Medicaid program called the Arizona Health Care Cost Containment System (AHCCCS, pronounced “access”). AHCCCS combines competitive bidding and capitation in an effort to constrain indigent health care costs while maintaining or improving access to mainstream care.\(^6\) But by design, AHCCCS has the potential to raise two significant barriers to care for the poor. First, eligible individuals must make an effort to enroll in the program before needing or receiving any care. Eligibility standards are such that less than one-half of the poor are eligible for the program. Second, enrollees must obtain all of their care from a relatively restricted number of providers. It is not enough that an enrollee obtains care from an AHCCCS-participating provider; they must obtain their care from a provider who is participating in the health plan with which they are enrolled. Such requirements create the potential that the poor may frequently be refused care.

These issues in part shaped the design of a survey on the access to health care for Arizona’s poor, which was conducted in the summer of 1984, sponsored by the Flinn Foundation and The Robert Wood Johnson Foundation. This survey, a repeat of a 1982 effort, contained an extensive set of new questions that attempted to capture the details of the experiences of respondents who reported that they were refused care for

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financial reasons or tried to get, but could not obtain, three specific types of medical services: emergency medical care, pediatric care, and prenatal care. This detail was possible because the large samples in the surveys -2,500 households in each were collected within a single state, and only included households below the federal poverty line.

Methodology

Overall, the methodology of the survey was closely modeled after previous national surveys on access to health care supported by The Robert Wood Johnson Foundation. Randomly selected self-weighted cluster samples of low-income families were drawn from geographical areas or census tracts within Arizona with 20 percent or more of the households below the federal poverty line. Each household was screened for income and family size, and those with income less than double the AHCCCS medically indigent ceiling were included in the survey. It is important to note that this ceiling is less than the federal poverty line: all respondents were poor, though only approximately one-half would qualify for the AHCCCS program.

In each household which passed the family size and income screen, one interview was held with a randomly selected adult, and, if children were present in the family, an adult proxy was used to collect data on a randomly selected child. Completion rates for selected households were over 90 percent. Interviews were conducted in both English and Spanish; the surveys were undertaken by Louis Harris and Associates.

There were four types of events covered by the survey: (1) a family member tried to obtain care but was refused for financial reasons; (2) a family member tried but was initially unable to obtain emergency care, (3) a family member tried but was initially unable to obtain care for a sick child in the household, and (4) a family member tried but was initially unable to obtain prenatal care.

Refused Care For Financial Reasons

The overall rate for cases when a member of a family was refused care for financial reasons was 5.4 per 100 poor Arizona households in 1982 and 6.9 per 100 poor Arizona households in 1984. The data for other subgroups is seen in Exhibit 1, which indicates that these events are occurring with sufficient frequency throughout the entire poor population to warrant detailed study. The rate has greatly increased in the population eligible for and/or enrolled in the AHCCCS program; as will be seen, some of the refusals do involve AHCCCS providers. Other subgroups with higher care refusal rates are hispanics, the unemployed, and the uninsured.
Exhibit 1
Arizona Poor Families Who Were Refused Care For Financial Reasons, 1982 And 1984

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Total</th>
<th>Eligible and/or enrolled in AHCCCS program</th>
<th>Not covered by AHCCCS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1982</td>
<td>1984</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1982</td>
<td>1984</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>5.4%</td>
<td>6.9%</td>
<td>4.1%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6.7%</td>
<td>8.1%</td>
<td>6.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Total</th>
<th>Eligible and/or enrolled in AHCCCS program</th>
<th>Not covered by AHCCCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>6.5</td>
<td>8.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7.2</td>
<td>9.6</td>
<td>7.2</td>
</tr>
<tr>
<td>Not in labor force</td>
<td>4.1</td>
<td>5.5</td>
<td>2.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Total</th>
<th>Eligible and/or enrolled in AHCCCS program</th>
<th>Not covered by AHCCCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insured</td>
<td>3.3</td>
<td>6.2</td>
<td>3.1</td>
</tr>
<tr>
<td>Uninsured</td>
<td>8.3</td>
<td>9.0</td>
<td>6.2</td>
</tr>
</tbody>
</table>

There were 171 households in which the adult respondent reported that they or someone else in their immediate household at some point in the previous twelve months were refused health care because of no health insurance, because of not being able to pay, because of not being covered by the AHCCCS program, or because of other reasons (such as being enrolled in AHCCCS but attempting to use an out-of-plan provider). Of the total, 133 were clearly for financial reasons, and a review of the verbatim responses of the remaining thirty-eight indicated that they were for other kinds of economic difficulties (for example, being eligible for but not yet enrolled in the AHCCCS program, or being enrolled with an AHCCCS plan but attempting to use a nonplan provider). All 171 cases are grouped together for these analyses.

**Where did the refusal occur?** Thirty-eight percent of the refusals were by county hospital outpatient clinics, emergency rooms, and free-standing clinics and 37 percent were refusals by private physician offices or private clinics. Most of the remainder occurred at noncounty hospital outpatient departments, clinics, and emergency rooms.

**Were these refusals due to AHCCCS?** A sizable portion, 39 percent, occurred with individuals who were in AHCCCS at the time of the refusal. Of these cases, 59 percent were refusals by AHCCCS providers to treat current AHCCCS patients. Some of these cases may have involved individuals who had lost eligibility and enrollment in AHCCCS, and were not aware of that change. Others may have involved a provider who, while participating in AHCCCS, was not a member of the specific plan of the respondent. The remaining cases involved people who went to a non-AHCCCS provider, or who were not sure as to the AHCCCS
participation status of the provider who refused the care.

Was care eventually received? In 52 percent of the total cases, care was eventually obtained from some other source. The remainder reported that they never obtained care for this episode. For those who received care after trying a second time, 37 percent received the care from a private physician office or a private clinic, while 31 percent received care from county hospital outpatient clinics, emergency rooms, and free-standing clinics. Of those who were initially refused care by a private physician and eventually received the care, 56 percent received it from another private physician, and 24 percent received it from a county facility. Of those who were initially refused care by a county facility and eventually received the care, 40 percent received it from another county facility, and 24 percent received it from a private physician.

How serious were these cases? The respondents were asked to assess the seriousness of the medical condition that was present at the time of the refusal, and to estimate the number of days that they spent in bed and days of reduced activity due to the condition. A case was categorized as very serious if the respondent categorized it as very serious and they had spent either three or more days in bed or had eight or more days of reduced activity. By this criterion, some 31 percent of the cases involved a very serious illness or injury.

### Tried But Could Not Get Emergency Medical Care

The overall rate for cases when a member of a family tried but was initially unable to obtain emergency care was 2.9 per 100 low-income Arizona households in both 1982 and 1984. The data for other subgroups is seen in Exhibit 2. Hispanic households and households with an unemployed main wage earner are more likely to encounter this barrier to care.

There were seventy-three households in which the adult respondent reported that they or someone else in their immediate household tried but could not get emergency medical care at some point in the previous twelve months. When asked why, 28 percent reported that it cost too much, 18 percent reported that they were not eligible for AHCCCS, 13 percent reported that they could not get an appointment, 12 percent reported that they were not covered by any insurance, and 4 percent reported that their physician said that their condition did not warrant emergency care. The remainder provided complex anecdotes which could not be clearly classified.

Only 37 percent of these cases occurred with individuals who were in AHCCCS at the time of the refusal. Of these, however, 74 percent were refusals by AHCCCS providers to treat current AHCCCS patients. As mentioned earlier, some of these cases may have involved confusion over
enrollment. The remaining cases involved people who went to a non-AHCCCS provider, or who were not sure as to the AHCCCS participation status of the provider who refused the care. Using the previously described algorithm, 47 percent of the cases were classified as very serious.

**Tried But Could Not Get Care For A Sick Child**

The overall rate for cases when a member of a family tried but was initially unable to obtain care for a sick child was 1.3 per 100 poor Arizona households in 1982 and 4.4 per 100 poor Arizona households in 1984. This increase occurred mostly in the population eligible and/or enrolled in the AHCCCS program. As seen in Exhibit 3, the increase occurred in both white and hispanic, employed and unemployed, and insured and uninsured households.

There were forty-three households in which the adult respondent reported that they or someone else in their immediate household were not able to obtain care for a sick child at some point in the previous twelve months. When asked why, 33 percent reported that it cost too much, 18 percent reported that they were not covered by any insurance, 13 percent reported that they could not get an appointment, and 10 percent reported that they were not eligible for AHCCCS. The rest provided other complex explanations.

Only 18 percent of these cases occurred with children who were in AHCCCS at the time of the refusal. Of these, however, 86 percent cases were refusals by AHCCCS providers to treat current AHCCCS patients.
As with the previous measures, respondents were asked to assess the seriousness of the medical condition that was present at the time of the incident. Based upon the same criterion, 35 percent of the cases involved a very serious illness or injury.

**Tried But Could Not Get Prenatal Care**

There were ten cases in which a member of household tried but could not get prenatal care. When asked why, three reported that they were not covered by any insurance, two reported that it cost too much, and two reported that they were not eligible for AHCCCS. Three reported that they were on AHCCCS at the time of their last pregnancy, and all three stated that it was their AHCCCS provider who would not provide prenatal care.

**The Words Of The Poor**

The interviewers asked the respondents to briefly provide any other details that they felt were relevant to these incidents. While statistics are the usual coin-of-the-realm in the health policy debate, these short descriptions from the poor of their own situation are also relevant. One aspect they highlight is the emotional stress associated with encountering barriers to medical care.
I was in pain. They only gave me pain pills and told me to go home and rest and stay in bed because of my financial situation and because I didn’t have insurance.

She lost her eyesight due to complications from diabetes and the time spent getting the money together for a medical visit.

She got worse and had to be hospitalized when she finally saw a doctor.

He was sicker longer than he should have been. He had an infected throat and needed antibiotics.

Felt real bad. Had nothing to look forward to, couldn’t find help for my asthma attacks; scared me.

Unable to get over illness. Have had pneumonia four times this year. Temperature gets extremely high. When ill, am unable to work. I don’t feel like doing anything, couldn’t care less about the world.

Slowly killing me. I don’t know what they’re going to or can do. They’re “looking into it” now. Either they’re gonna do it or I’m gonna lay down and die. Had they given me proper care two years ago, I wouldn’t be in bed now.

It was a disadvantage to me, demeaning because of it. I wasn’t in position of paying. I chose to stay home with my infant instead of working.

It got her depressed she was bleeding. The doctor told her she had cancer . . . she felt she wasn’t going to live. Then, she went across the border to Mexico . . . doctor there said she had a miscarriage. She felt better. The baby was four months old. We don’t see that doctor anymore. We go across the border. It’s too expensive here; my daughter had bad cramps . . . we took her to doctors . . . cost $1,200 . . . I’m still paying for it. I’m on Social Security . . . I’m disabled.

He’s still hurting, can’t walk right, takes a lot of pills. Sometimes the pain is so bad I give him some of my pills. He can’t work all the time.

Made you want to kill yourself, you’d rather die, you would have died had you not been treated. I had cancer, was ineligible for AHCCCS program.

Conclusions

The reports by the poor of being refused treatment or being unable to obtain care after trying to do so are serious matters. The indications from
Arizona are that most of these problems are a product of inadequate, financial resources—either inability to obtain health insurance, or inability to qualify for enrollment in the state’s prepaid Medicaid program. However, enrollment in AHCCCS does not eliminate the occurrence of these incidents. Many of the cases involved an AHCCCS patient being refused service by an AHCCCS provider. While some of these cases are justifiable, in that an enrollee may have gone to a provider in a different plan, this is still a serious problem, as they indicate that confusion over eligibility and enrollment on the part of both patient and providers can occur in a system of prepaid, capitated care.

Extrapolating from these more than 250 events to the state’s total poor population is difficult, but should be attempted in order to estimate the magnitude of the problem. If we limit the number of occurrences to the approximately 100 cases which were classified as very serious, involving lengthy bed-days, and considering that the total sample consisted of 2,500 low-income households, it is reasonable to argue that one in twenty-five poor households in Arizona encounters some sort of direct provider refusal to provide care in a year for a family member with a serious health problem. Similar rates are likely to exist in other states with equally restrictive Medicaid eligibility requirements.

While competition and prepayment may control Medicaid program costs, there must be sufficient communication with the eligible population and program enrollees so that individuals understand that they must determine whether they are eligible for Medicaid prior to their needing medical care and that they should go to their assigned providers after enrollment for their care. At the same time, there should also be sufficient oversight, possibly through an independent patient advocacy office, to assure that enrollees can obtain the services that government is paying these plans to provide. More importantly, these results indicate that care refusals will occur if eligibility is narrowly defined. Competition can only be a viable indigent health policy if all of the poor are entitled to some minimal form of health coverage.
NOTES

7. Aday et al., Health Care in the U.S.; and Aday et al., Access to Medical Care in the U.S.
9. Many of these comments are translations from Spanish or are from respondents who speak English as a second language.