Original Research

Effects of being uninsured on ethnic minorities' management of chronic illness

ABSTRACT ● **Objective** To compare the effectiveness with which insured and uninsured persons with chronic illnesses managed their health care. ● **Design** Recruited volunteers diagnosed with a variety of chronic illnesses who underwent 3 semistructured interviews in a 1-year period. ● **Setting** Volunteers were recruited through referrals, flyers, and face-to-face contacts from community health clinics, senior centers, acute care hospitals, and home care services in 2 urban counties in California between December 1997 and December 2000. ● **Participants** A total of 297 persons between the ages of 23 and 97 years (35% African American, 33% Latino, and 32% Filipino American), of whom 42 (14%) had no health insurance. ● **Main outcome measures** Qualitative analysis of interview data compared insured and uninsured respondents on a series of components of chronic illness management, including control over illness, frequency of health crises, procuring medication, use of medication, understanding of the illness, knowledge of self-care measures, and awareness of risk factors. Whether respondents were under the care of a regular physician was also assessed. ● **Results** Compared with insured respondents, uninsured respondents were much less effective at managing their illnesses. The uninsured had poorly controlled illnesses, frequent health crises, difficulty procuring medication, used medication incorrectly, demonstrated poor understanding of their illness, and displayed little knowledge of self-care measures or risk awareness. They rarely had a regular physician or attended a specific health clinic. ● **Conclusions** The findings suggest that not only did uninsured persons with chronic health conditions lack adequate health care, their illnesses were also poorly controlled. Inadequately educated about their health, uninsured persons lacked the information, insight, and tools that would have allowed them to manage their illnesses more effectively.

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Whether or not people have medical insurance has a major effect on their health. In 1999, 1 of 6 people living in the United States was uninsured.[1] People in ethnic minority groups are even more likely to be uninsured[2]: 1 of 3 Hispanics and 1 of 4 African Americans are without health insurance.[3,4] Although the challenge of providing effective health care to the 43 million Americans who do not have medical insurance is substantial, little or no research has addressed how those patients who are especially vulnerable—uninsured patients who suffer from chronic illnesses—manage their health and health care on an ongoing basis. I present findings from a qualitative study of African American, Latino, and Filipino American respondents. The main objective was to compare the management of chronic illness among those who were insured with those who were uninsured.

Summary points

- Of 297 persons in 3 ethnic groups, 42 (14%) had no health insurance
- The illnesses of uninsured persons were poorly controlled, and uninsured people reported ongoing health crises
- The uninsured rarely had a regular physician or consistently used a specific health clinic, constantly struggled to secure medication, lacked understanding of their illnesses, and rarely practiced self-care

METHODS

The findings are based on 2 large qualitative studies that examined the same questions about the daily management of chronic illness but included different age groups. They are combined here to illustrate the issues that uninsured people address across the life span. Respondents were from 3 ethnic groups: African Americans, Latinos, and Filipino Americans; they were between the ages of 23 and 97 years, and they had 1 or more chronic illnesses. The most common illnesses were diabetes mellitus, asthma, and heart disease or hypertension. The total sample included in the study was 297: 105 African Americans, 97 Latinos, and 95 Filipino Americans. The total number of people who were uninsured was 42 (14%): 14 African Americans, 17 Latinos, and 11 Filipino Americans.

The study protocol and consent form were approved by the Institutional Review Board, Committee on Human Research, University of California, San Francisco, School of Medicine. Respondents were recruited through community health clinics, acute care hospitals, home care services, and other sources in 2 urban counties between December 1997 and December 2000 (table 1). The criterion for entry into the study was the presence of 1 or more chronic illnesses. The sample reflected a range of illness severity from mild to severe.

Following key tenets of the in-depth interviewing approach,[5-8] respondents were interviewed 3 times in a 1-

Table 1 *Method of recruitment*

Sources	Insured Frequency, no. (%) (n = 255 [86%])*	Uninsured Frequency, no. (%) (n = 42 [14%])*
Senior centers	58 (23)	6 (14)
Clinics	57 (23)	10 (24)
Field contacts	36 (14)	6 (14)
Participant referrals	35 (14)	10 (24)
Home care services	29 (12)	0
Flyers	20 (8)	8 (19)
Religious organizations	10 (4)	2 (5)
Hospitals	6 (2)	0

*Number represents all available data.

year period. Hour-long interviews were semistructured and addressed experiences with illnesses, daily living routines, economic situation, and use of and access to health care. Interviews were tape recorded and transcribed verbatim.

Respondents were interviewed in their language of choice by interviewers who were members of the same ethnic group. African Americans were interviewed in English. With 3 exceptions (interviewed in English), Latinos were interviewed in Spanish, and Filipino Americans were interviewed in Tagalog. Limitations: Interviewers translated and transcribed interviews they had conducted because of a dearth of trained people who were adequately bilingual to do the transcribing.

Qualitative content analysis was used to analyze the data.[9] The data were divided into the 3 groups; each group was analyzed separately, then cross-group comparisons were made. A specific procedure was followed in the analysis:

- Core categories that repeatedly reappeared in the data were identified[10]
- Selected transcripts were read by the entire team to generate consensus in coding categories, which led to the development of codes. This was followed by successive phases of trial coding until a level of agreement of 95% or more was reached by pairs of coders. This process resulted in 97 discrete codes
- The entire data set was coded for specific topics using a data-sorting software program (Nudist)
- A case-by-case narrative analysis was conducted, in which emphasis was given to how people portrayed their illnesses. Research has shown that such subjective reports are accurate reflections of illness severity[11]

RESULTS

Demographics

Table 2 shows the demographic information of respondents.

Health care and poorly controlled chronic illness

The major finding to emerge from this research was that most of the uninsured respondents' illnesses were poorly controlled. A major difference could be discerned between the insured and the uninsured: whereas the insured reported occasional health crises (symptoms experienced as frightening or out of the ordinary, for which medical care is usually sought), the uninsured reported an ongoing chain of such health crises.

With few exceptions, the uninsured did not have a regular physician or a specific health clinic they consistently used; they sought their medical care from emergency departments, free clinics, or low-income clinics that had sliding scales. Small neighborhood clinics that operated free of charge were most heavily frequented. African Americans and Latinos were able to identify sources of free care much less frequently than were Filipino Americans because of the distribution of free clinics.

In almost all cases, the uninsured reported that they sought care only when they had persistent symptoms that interfered with their daily lives. Lack of money was the primary reason given for not seeking health care, and respondents often reported feeling extremely ill before they sought care. Those who had identified and used a free clinic were much less likely to delay.

Whereas the insured reported an infrequent use of emergency departments, the uninsured reported that they often found it necessary to seek emergency department use because of their acute symptoms. Almost without exception, visits to hospital emergency departments were described as emergencies, such as intractable episodes of asthma or episodes of severe dizziness by patients who had hypertension. The uninsured reported that they were usually given a limited supply of medication but rarely reported being sent home with a treatment plan. They were unaware of any reevaluation of their condition on subsequent visits to a community clinic.

Getting medication

Most of the insured had a regular physician, had complex medical regimens that included daily use of medication, and their illnesses were under control. In contrast, the uninsured reported being in a constant struggle to secure adequate medication. They said that they could not control their illnesses and described unremitting symptoms, functional limitations, and frequent health crises.

Three specific problems could be identified for the uninsured with respect to medication (see box). The first of these was getting appropriate medication. Some respon-

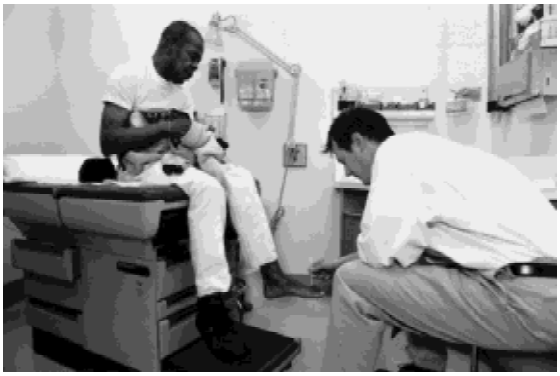
The uninsured: problems associated with getting medication

- Reliance on free samples and over-the-counter medication
  "I was using a lot of Primatene, NyQuil. This stuff [asthma] just kept bothering me, and finally it got to the point where I had to go to the hospital. I came up here, and I was pretty sick."
- Effects of being unmedicated
  "When I catch colds, I can't catch my breath and have to go to the emergency [because of asthma]. If I catch a cold, then I always have to go. I just can't breathe. I'm gagging for air. It's like, 'Oh, my God, am I going to die?' "
- Reasons for not seeking medication
  "If I go to the hospital [for insulin], they will charge me a lot. I am not working. I can't afford to pay."
- Difficulties getting medication
  "The prescription they gave me, I can't seem to get that prescription again. It takes all the fluid out of your lungs. I can't seem to get those pills. I need [them], but I can't get them."
- Using medication inappropriately
  "What I am doing is that 1 of my friends with asthma is giving me medicines from her own, and also my sister is giving me hormones because she uses hormones, too."

dents were unmedicated and others were undermedicated. The uninsured who had asthma or hypertension were most frequently undermedicated.

The second problem respondents reported about medication was having an adequate supply. Those who had had a chronic illness for years recognized the need to keep up with their regular regimen of medication and were preoccupied with how to get more medication.

The third problem was the inappropriate use of medication. Half of the uninsured respondents did not use their medication correctly and reported several ways of dealing with dwindling medication supplies: cutting down on the dose and taking it half as often until it ran out, taking medication prescribed for daily use only when symptoms occurred, or sharing others' medication.



Alain McLaughlin

Insured patient on a routine visit to his physician

Table 2 *Demographics of interview 297 subjects*

Demographics	Insured Frequency, no. (%) (n = 255 [86%])*	Uninsured Frequency, no. (%) (n = 42 [14%])*
Age, yr		
Range (mean)	21–97 (63.9)	23–95 (54.2)
Sex		
Women	157 (62)	31 (74)
Men	98 (38)	11 (26)
Marital status		
Married	93 (37)	16 (38)
Unmarried (widowed, divorced, separated, never married)	162 (64)	26 (62)
Education		
No education	3 (1)	2 (5)
Grade school	85 (34)	16 (38)
Some high school	42 (17)	8 (19)
High school graduate	51 (20)	6 (14)
Some college or vocational training	23 (9)	5 (12)
College graduate	41 (16)	2 (5)
Postgraduate	6 (2)	2 (5)
Other	3 (1)	1 (2)
Work life		
Retired	168 (66)	13 (31)
Currently working	42 (17)	15 (36)
Homemaker	20 (8)	7 (17)
Disabled	14 (6)	0
Unemployed	9 (4)	7 (17)
Student	2 (1)	0
Occupation		
Higher Exec, major professional	1 (<1)	0
Business manager, administrative minor professional	32 (13)	2 (5)
Technical semiprofessional	13 (5)	1 (2)
Clerical, sales	23 (9)	4 (10)
Skilled labor	50 (20)	3 (7)
Machine operation, semiskilled	50 (20)	10 (24)
Unskilled labor	52 (20)	13 (31)
Farm labor, menial	10 (4)	1 (2)
Homemaker	20 (8)	7 (17)
Student	2 (1)	0
Never worked	2 (1)	1 (2)

*Number represents all available data.

Lack of knowledge about illness and self-care

Those who were insured and had a regular physician were much more knowledgeable about their illnesses than were the uninsured. The insured recited danger signs they watched for and illness triggers they tried to avoid. Although the insured did not always follow guidelines for their illnesses, they were much more likely to know about them than the uninsured. This research has previously demonstrated the importance of patients' knowledge of their illnesses for effective illness management.[12] A new finding is the extent to which lack of knowledge adversely affects people's ability to manage their chronic illnesses (see box). With few exceptions, the uninsured demonstrated little understanding of their illnesses or what to do about them. They were less effective at symptom recognition and were less knowledgeable about related conditions, such as foot infections in those who had diabetes.

The insured were much more likely than the uninsured were to think in terms of self-care. They reported that their physicians explained to them about exercise, diet, and the importance of not smoking. The uninsured rarely made such statements. More than half of the uninsured did not follow any dietary modifications, exercise, or other risk-avoidance behaviors. In contrast to the insured, the uninsured described home remedies as replacing a medical regimen rather than adding to it.

The uninsured: lack of information about illness

- Lack of understanding of illness
  Unmedicated Latino previously diagnosed with insulin-dependent diabetes: "There are moments when I feel tired, sleepy. That's what bothers me the most. I feel lazy, like I don't want to get up. I spend my time drinking water and going to the bathroom. Sometimes I lose weight, and then suddenly I start to gain weight back. Sometimes I weigh 126, and then in 1 week I gain until 140 or 145. Right now I am losing weight again. That is what I don't understand."
- Lack of recognition of danger signs
  Latina who had diabetes: "My leg was swollen like a balloon. I thought it was my arthritis."
- Home remedies as replacement for medical regimen
  Unmedicated African American who had asthma: "My sister told me to drink a lot of water, or coffee, when I'm having the asthma attacks. Hot coffee. Just those 2 things."
- Desire for more information
  African American with hypertension and asthma: "I like a doctor that is not just going to give you pills and send you out the door but is going to explain why you have this problem, what you can do for this problem, and how you can solve the problem."

DISCUSSION

People with chronic illnesses who are uninsured face great difficulties in managing their illnesses. Ongoing contact with physicians fosters more comprehensive health awareness that informs illness management. Effective illness management has a battery of components, including symptom recognition; understanding how a particular illness works; and following a daily regimen that includes regular medication use, self-care practices, and risk awareness and prevention. The uninsured are simply unable to articulate these different components. They do not think about their illnesses in the same comprehensive way as do the insured. Their approach is piecemeal, an apparent result of their fragmented and infrequent medical care.

TREATING UNINSURED PATIENTS

What can physicians do who serve uninsured patients who are chronically ill, despite the current constraints of the health care system? Individual physicians can make a difference, in 3 main ways.

First, physicians need to be alert to patients who are unmedicated or undermedicated. Access to medication postpones the recurrence of acute illness episodes.

Second, physicians can promote the concept of managing the chronic illness to patients, who need to learn that there is more to chronic illness management than medication, however important medication may be. Physicians can help uninsured patients become better illness managers by talking with them about the specifics of chronic illness management. Although insured patients consistently receive such information, uninsured patients apparently do not. Hearing the same information repeated over time, even by different physicians, helps to reinforce it. Providing written guidelines in the patient's first language may facilitate this process.

Third, physicians should develop a treatment plan with uninsured patients. Discussing what would be a reasonable treatment plan—even with patients who may never be seen again—helps to educate the patient about the medical management of the chronic illness, information that patients carry with them to the next medical encounter. Such guidelines are essential to reduce subsequent health crises.

Despite perceptions of poor, uninsured persons as inattentive, problem-ridden, and difficult to treat,[13] the uninsured are trying to control their illnesses. Although they often have many other concerns, such as securing adequate food, shelter, finances, and caring for family members, they appreciate information about illness management and try to act on medical advice.

This research attests to the critical importance of free community clinics for the uninsured. The capacity of the health care safety net—a loosely organized collection of publicly subsidized hospitals, local health departments, clinics, and individual clinicians[14]—to provide care for those without insurance is increasingly at risk because of cutbacks in public funding and pressures from the marketplace.[15] Such facilities provide a much-needed resource

for the uninsured and undoubtedly play a substantial role in decreasing mortality. In the continuing absence of health insurance, increased underwriting of the cost of such health care services is essential to reduce morbidity and mortality among the uninsured.

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