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Access to Health Insurance: Experiences and Attitudes of Those With Genetic Versus Non-Genetic Medical Conditions

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Abstract

While studies reveal that individuals with both genetic and other chronic medical conditions have difficulty obtaining health insurance, no large-scale studies have compared the health insurance experiences of these groups. The goal of this study was to document and compare the health insurance experiences, attitudes, and beliefs of persons with genetic conditions to those of persons with or at risk for other serious medical conditions. We interviewed approximately 100 adults or parents of children with one of each of the following medical conditions: sickle cell disease (SCD), cystic fibrosis (CF), diabetes, and HIV, and 200 adults with or at risk for breast (BC) or colon cancer (CC). The interview included items related to respondents' experiences and attitudes regarding health insurance. Twenty-seven percent of 597 total respondents self-reported having been denied health insurance or offered insurance at a prohibitive rate. Respondents with single-gene disorders (CF and SCD) were twice as likely to report this as those with non-genetic conditions. Legislation that exists to limit genetic discrimination in insurance addresses genetic risks or traits only, however, rather than protecting those with actual disease. Thus, current legislation may not address the challenges faced by individuals like those in this study, who try to maintain access to health insurance when they or their children are symptomatic with a genetic or other serious health condition. More than one-third of all respondents thought there was a high chance they would be denied health insurance in the future or their insurance would become unaffordable. That individuals with all six health conditions expressed concern regarding their

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ability to obtain future health insurance suggests policy proposals should be broad-based, addressing the needs and concerns of individuals with diverse health conditions.

Keywords

access to health insurance; genetic discrimination; hereditary disease; cross-sectional survey

INTRODUCTION

Access to health insurance has become an increasing concern as more and more individuals become uninsured each year. Currently, 46.1 million Americans have no health insurance and the number of uninsured has grown by over 6.5 million since 2000 [Kaiser Family Foundation, 2006]. Due to the high costs of health care in the United States, a lack of health insurance effectively limits an individual's access to health services [NIH/DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, 1993]. In 2003, nearly half of uninsured adults postponed seeking medical care, and over a third reported that they needed but did not obtain care in the past year [Kaiser Family Foundation, 2005].

Access to health insurance can be a particular challenge for those with both minor and major pre-existing health problems. A recent study by the Kaiser Family Foundation found that individual applicants with at least one pre-existing condition often are charged higher premiums than those with no such conditions, or are unable to obtain health insurance at all [Pollitz et al., 2001]. In the study, 19 health insurance companies from six different states were sent the profiles of seven hypothetical consumers who had a variety of health problems ranging from hay fever to HIV infection. The hypothetical consumers were unable to obtain a standard rate of coverage 90% of the time; furthermore, most of those who were accepted for coverage had benefit restrictions (28%), premium surcharges (13%), or both (12%). Those with HIV were rejected by all companies and, in general, the more severe the health problem, the less likely individuals were to be offered a policy.

There is also evidence that individuals with genetic conditions, in particular, face difficulty obtaining health insurance. Geller and colleagues documented cases of employment and insurance discrimination against patients diagnosed with several genetic conditions including Huntington's disease, hemochromatosis, phenylketonuria (PKU), and mucopolysaccharidoses (MPS). The study found that individuals with all four genetic conditions reported difficulty obtaining health insurance even though some of the conditions, such as hemochromatosis, are associated with no excess mortality or morbidity when controlled [Alper et al., 1994; Geller et al., 1996].

Insurance discrimination has also been documented against people who are healthy themselves but have a genetic predisposition for an illness [Hudson et al., 1995]. A recent survey conducted among individuals with a family history of a genetic condition found that 22% reported that they had been refused health insurance coverage because of their genetic risk, regardless of whether they were sick [Hudson et al., 1995]. Another 13% believed they had been denied or let go from a job because of their family history.

Thus, while evidence exists that individuals with both genetic and other types of medical conditions have experienced difficulty obtaining health insurance, no large-scale studies have compared the health insurance experiences of these two groups. Moreover, while considerable commentary exists concerning the potential for genetic discrimination, only a few studies have gathered systematic data from individuals documenting their actual experiences. Since much legislation regarding health insurance has focused on genetic discrimination specifically [Annas et al., 1995], it is important to examine the assumptions underlying such legislation by documenting whether experiences of persons with genetic conditions differ from those of persons with other conditions.

The goal of this cross-sectional interview study was to document and compare the experiences, attitudes, and beliefs of persons with genetic conditions, defined here as single-gene disorders (cystic fibrosis [CF] or sickle cell disease [SCD]) to those with other serious medical conditions of complex etiology (diabetes, HIV, breast cancer [BC], or colon cancer [CC]). Also included were individuals with a strong family history of BC or CC, referred to here as “at risk.” All groups were compared in terms of their beliefs and experiences obtaining and maintaining health insurance coverage and in terms of their experiences with insurance discrimination.

MATERIALS AND METHODS

Study Participants

Study participants were enrolled from March 1996 to February 2000. Convenience samples of approximately 100 participants each were recruited who had CF, SCD, DM, or HIV. Eligible respondents included both adults (aged 18–64) diagnosed with the condition (CF, SCD, diabetes, or HIV) and parents of children diagnosed with the condition (CF, SCD, or diabetes). Also recruited were 100 adults previously diagnosed with (n=50) or with a family history of (n=50) BC, and 100 adults previously diagnosed with (n=50) or with a family history of (n= 50) CC.

Respondents were recruited from clinics or ongoing research studies of the Johns Hopkins Medical Institutions, disease registries of the Maryland Department of Health and Mental Hygiene, and advertisements in Baltimore newspapers. These six sub-populations were included to represent a mixture of single-gene disorders and disorders of other etiology, to represent more and less stigmatizing conditions, and to create an overall sample that was heterogeneous in terms of race and class. Target sizes were based on power calculations designed to allow comparisons between and among disease groups for key research questions.

Throughout this article, we use the term “affected adults” to mean adult respondents themselves diagnosed with the medical condition, “parents” to mean respondents with a child with the medical condition, and “at-risk adults” to mean respondents with a family but no personal history of cancer. The conditions referred to herein as “genetic” are defined as single-gene disorders with predictable patterns of inheritance and penetrance (CF and SCD).

The Interview

One structured interview was administered by a trained interviewer to each participant. Half the participants were interviewed in person and half were interviewed via telephone, based on the respondent's preference. Written informed consent was obtained from those interviewed in person; oral consent was obtained for telephonic interviews. Interviews lasted approximately 45 minutes, and participants were compensated \$20 plus travel expenses. This protocol was approved by IRBs at Johns Hopkins Medical Institutions and the Maryland Department of Health and Mental Hygiene.

The interview included both quantitative and qualitative items related to knowledge, attitudes, and experiences with privacy and disclosure, confidentiality and discrimination, employment, health insurance, and demographic information. Data are reported here from items that focused specifically on respondents' experiences and attitudes regarding health insurance. Data from other items have been reported previously [Kass et al., 2003, 2004; Plantinga et al., 2003; Johnson et al., 2005]. Quantitative items either had binary response options ("good idea"/"bad idea") or ordered response options ("strongly agree"/"agree"/"neutral"/"disagree"/"strongly disagree"). For purposes of analysis, "strongly agree" and "agree" were collapsed into one category, and "strongly disagree" and "disagree" were collapsed. Qualitative questions were open-ended and generally paralleled topics raised in quantitative items.

Analysis

Responses to quantitative items regarding health insurance were cross-tabulated with demographic variables, and Pearson's χ^2 test for independence was performed on these contingency tables. Responses to relevant items were also examined by disease group (CF, SCD, diabetes, HIV, BC affected, BC at-risk, CC affected, and CC at-risk) and also by "genetic" versus other conditions. Adjusted odds ratios were calculated with logistic regression models when the outcome was binary (e.g., "yes" or "no"). Ordinal logistic regression models (also known as proportional odds models) were used for calculating odds ratios for categorical outcomes with inherent ordering (e.g., "agree," "neutral," or "disagree"). All regression models were adjusted for age, income, marital status, race, and employment status. All analyses were performed using Stata v.7.0 (College Station, TX).

RESULTS

A total of 602 individuals completed interviews. Three interviews were excluded because participants were over age 64, and two were excluded due to significant missing data, resulting in a final sample size of 597. Table I presents the demographic characteristics of the study sample. There was significant variation among disease groups for a number of demographic characteristics including marital status, race, education, and income.

Experiences With Health Insurance

Over 90% of study participants reported that they had health insurance (Table II). Individuals with HIV were the least likely to report having health insurance. The likelihood of having health insurance did not differ significantly by whether respondents had a single-

gene condition or another condition. Analyses changing the definition of “genetic” disease to include those with or at risk for cancer were also performed. They are not presented as they did not differ significantly from results presented here.

The vast majority of respondents (89.7%) reported that they obtained their health insurance through either their employer (59.4%) or their spouse’s employer (30.8%). Further, almost half of the employed individuals (48.9%) reported feeling they could not leave their jobs because they would lose health insurance (74.4% among those with CF, overall χ^2 , $P < 0.001$). Qualitative data revealed many participants worried about retaining insurance coverage if they became too sick to work. Other participants reported remaining at a job that they might otherwise have left due to fear of losing their health insurance coverage. Qualitative data are summarized in Table III.

Sixty-three percent of insured participants reported they had a choice of plans when they obtained coverage. Participants with SCD (45.9%) or HIV (47.8%) were least likely to report having had a choice of plans ($P < 0.001$) and were also most likely to report having Medicaid rather than private coverage (40.4% and 36.3%, respectively vs. 16.1% overall, $P < 0.001$).

Twelve percent of respondents said they had tried to obtain additional health insurance after learning of their condition. Individuals with genetic conditions were more likely to report trying to obtain additional health insurance compared to individuals with other conditions (χ^2 test, $P < 0.001$). Of those who tried to obtain additional coverage, 67.2% reported being successful. The ability to secure additional health insurance coverage did not differ by whether participants had a genetic or non-genetic condition.

Attitudes and Beliefs Regarding Health Insurance

Most study participants agreed that people have little power to stop health insurance companies from getting medical information about them (Table IV). African-American participants were more likely to agree than were white participants (OR = 1.7, $P = 0.004$). This response did not differ by disease group, as measured by Pearson’s χ^2 test.

Individuals with HIV were most likely to believe (68% vs. 49% overall) that healthcare providers would not send specific test results to health insurance companies if asked not to ($P < 0.001$). At-risk respondents were significantly more likely than all other respondents to agree that doctors should be punished if they release medical information to insurance companies without permission (82.2% for BC at-risk, 81.6% for CC at-risk compared to 73.0% overall, $P < 0.05$). No significant differences were seen for any items measuring attitudes and beliefs about health insurance between those with genetic and other conditions.

Experiences With Insurance Denial

Overall, 27% of participants reported they had been denied health insurance or offered it at a prohibitive rate (Table V). Individuals with genetic conditions were more likely to report these problems than those with non-genetic conditions (37.3% vs. 21.6%, $P < 0.001$). In regression analyses, those with genetic conditions (CF and SCD) were twice as likely to report having been denied health insurance compared to those with non-genetic conditions

adjusting for age, income, marital status, race, and employment status. Further, 41% of adults themselves affected with the condition reported having been denied insurance and/or having it offered at a prohibitive rate, whereas 24% of parents of affected children reported these problems ($P=0.002$).

Eight percent of participants overall believed their insurance rates had been raised because of their medical history; this did not differ by disease group. Eighteen percent of participants reported their health insurance company had limited their coverage for care related to their condition while still covering other problems. Individuals with genetic conditions were more likely to report having their coverage limited compared to individuals with other conditions (23.5% vs. 14.2%, $P < 0.05$).

A small proportion (3%) of respondents reported they had withheld information from health insurance companies; this was most likely to be reported by those with HIV (8.8%, $P < 0.05$). Other respondents suggested in qualitative comments that while they did not withhold information from an insurance company, they had decided not to apply for insurance after reading the questions asked on applications, especially when answering those questions would reveal a pre-existing condition that they assumed would lead to denial of coverage. Moreover, a small proportion of participants (5.5%) reported they had decided not to use health insurance to pay for treatment in order to keep a medical condition private; this was most often reported by those with HIV (17.7%, overall χ^2 , $P < 0.05$).

Perceptions of the Likelihood of Future Risks Associated With Health Insurance

The majority of respondents (59.4% overall; 71.7% of those with BC, overall χ^2 , $P < 0.05$) believed it was likely a health insurance company could obtain medical information about them without their permission (Table VI). Similarly, 67% of participants (84.8% of those with CC, overall χ^2 , $P < 0.01$) believed there was a high chance a health insurance company could get medical information about them from a computerized record without them even knowing. Individuals who were white, who were over 40, or were unemployed were most likely to believe health insurance companies could get information about them from a computerized record without their knowledge. The responses did not differ significantly by whether respondents had a genetic or other condition.

Many respondents also were concerned about future access to health insurance. Overall, 37% of respondents thought there was a high chance that in the future they would be denied health insurance or it would become unaffordable. This belief did not differ significantly by disease group or by genetic condition. White respondents were significantly more likely to express this belief than African-American respondents (OR=1.75, $P < 0.001$). Further, 43% overall thought, if they were to get a new insurance policy, there was a high chance it would not cover all their needs.

Qualitative responses provide additional data on participants' worries about future access to health insurance (Table III). While some worried generally about a loss of insurance, others worried about it in relation to possible loss of employment. Participants worried that if they lost their job they would be unable to obtain new coverage or their new policy would not cover all of the same services as their current policy. Participants also expressed worry that

health insurance companies would limit their coverage in some way and they would be unable to afford either prescriptions or other necessary medical care. Several individuals also worried that they would reach a lifetime maximum cap on their insurance and that the insurance companies would then refuse to pay for additional medical care. Parents worried about their affected children's ability to obtain health insurance once they were ineligible for coverage under their parents' policy.

Participants at risk for a genetic condition were particularly worried about the privacy of genetic test results. They worried that a genetic test would become part of their medical record and affect their ability to obtain insurance coverage. Concern about the privacy of test results led several respondents to comment that although they had a familial risk for a certain disease, they had decided to forgo genetic testing for fear the results could affect their eligibility for health insurance and/or cause their insurance premiums to rise.

DISCUSSION

The vast majority of participants in this study (95%) reported that they currently had health insurance. Moreover, among participants who reported trying to obtain additional health insurance after learning their condition, 67.2% reported being successful. At the same time, 27% overall reported having been denied health insurance or having it offered at a prohibitive rate, and more than one-third of respondents thought there was a high chance that they would be denied health insurance in the future, or that their health insurance would become unaffordable. Participants were especially worried that if they lost their current insurance, the new policy would not cover all of their medical needs and they would be unable to afford either prescriptions or other necessary medical care. Parents also worried that their children would be unable to obtain health insurance once they were ineligible to be covered by their parents' policies. While at-risk respondents reported fewer experiences with denial or prohibitive rates, they had greater worries about their future health insurance coverage. Presumably, this reflects either a fear that access would be limited if they developed BC or CC, or that insurance companies in the future will limit their access by virtue of their at-risk status itself.

While health insurance refusal was reported by some proportion of every disease sub-group, those with genetic conditions were significantly more likely to report these problems. Individuals with genetic conditions were twice as likely to report having been denied health insurance altogether or having it offered at a prohibitive rate than those with non-genetic conditions after adjusting for age, income, marital status, race, and employment status. In contrast, there were no significant differences by disease group in participants believing insurance rates were raised because of their medical history.

Insurance denial generally happens only when one applies for individual coverage, as group policies rarely screen individual members. Therefore, we attempted to compare the reported experiences of insurance denial or prohibitive rates between those who currently have individual versus group coverage. As it turned out, only 22 of the 597 study participants reported having individual policies. Thus, we were unable to examine this question. That only 4% of our study population currently had individual coverage, however, is itself

noteworthy, given that the national rate of individual health insurance coverage is 10% [DeNavas-Walt et al., 2005]. One might speculate that study participants, keenly aware of their chronic condition and a need for ongoing medical care, may have made concerted efforts to get into a group plan following their diagnosis. Some sub-populations included here also had greater rates of Medicare or Medicaid coverage, which was likely also due to their disability, and contributed to the higher rate of group coverage.

The high rate of reports of insurance problems, given the parallel high rate of group coverage, then, could emerge from one of the two explanations. Either participants were reporting that even their group coverage seemed unaffordable to them, given that many group policies now require employees to contribute larger shares of premiums. Alternatively, our respondents were reporting on events in their past when they indeed had tried to apply for individual coverage. Indeed, the study question asked if they had *ever* experienced insurance denial or offers at prohibitive rates.

A limitation of this study is that all data, including accounts of insurance denial, were self-reported. Due to the nature of this interview study, we were unable to buttress these self-reports with supporting documentation from other sources. Thus, we are unable to know with certainty whether more problems with insurance access were experienced by those with genetic conditions, or whether, when an insurance rejection occurred, these participants were more sensitive to the possibility of disease-based discrimination. At the same time, it is unlikely that all instances reported by participants were due to participants lying, misunderstanding the question, or misattributing the cause of their insurance denial or prohibitive rates. Nationally, 13% of those who apply for individual health insurance are denied coverage altogether, and 18% are offered coverage at a higher premium and/or with exclusions [American Health Insurance Plans, Center for Policy and Research, 2006], lending some validation for the rates reported here among persons who all have a chronic condition themselves or within their families. A study from the Kaiser Family Foundation further supports the notion that individuals with chronic conditions should be legitimately concerned about health insurance access. In the Kaiser study, even people with minor health conditions such as allergies were denied health insurance coverage altogether or charged a higher initial premium [Pollitz et al., 2001].

It is a further limitation of our own study that the question used to explore insurance access problems was overly broad. In the interview, participants were asked whether they had ever been denied insurance or been offered at a prohibitive rate. In retrospect, it would have been better to separate these questions, as we were unable to distinguish insurance denial from prohibitive rates in interpreting respondents' experiences. Moreover, the questionnaire did not ask respondents if they were aware of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986 which allows individuals to continue to purchase health insurance, at their own expense, for up to 18 months when they leave a job where they had been receiving insurance.

There are additional limitations to this study. First, HIV has generally been viewed as a more stigmatizing condition than the other conditions in this study, and thus, the results from this group may have had significant influence on the aggregate experiences of those with "non-

genetic” conditions. Also, our operational use of the terms “genetic” and “non-genetic” reflected policy and not biological considerations. Many diseases have genetic components, including many, if not all, of the conditions we called “non-genetic.” We categorized only the two single-gene disorders as genetic in order to better approximate how policy makers and insurance companies have, in the past, been able to classify individuals. We are aware, however, that what these communities treat as a genetic condition is also a moving target. It should be noted that we reanalyzed our data using different definitions of “genetic” versus “non-genetic.” However, the results of these additional analyses did not differ significantly from the results presented here. A final limitation is that although our study involved detailed interviews of nearly 600 interviews from eight study populations, and predominantly from one U.S. city, these populations are not necessarily representative of individuals with other chronic and/or genetic conditions and/or in other parts of the United States.

Despite these limitations, the majority of subjects in this study, regardless of what type of condition they had, harbored a number of worries regarding their future health insurance coverage. While individuals with genetic conditions were more likely to report experiences of insurance discrimination, all individuals, regardless of genetic etiology, expressed worry about future access to and adequacy of health insurance.

While there are several recent editorials in the literature stating that genetic discrimination either does not exist or is a rare phenomenon [Wertz, 2002; Joly et al., 2003; Nowlan, 2003], data from this empirical study suggest that a higher proportion of individuals with genetic conditions have experienced health insurance discrimination in the past compared to people with other types of chronic medical conditions—reinforcing the evidence that insurance companies have distinguished between genetic and other kinds of conditions in making coverage decisions. This study confirms the findings of other empirical studies that have found evidence that individuals with genetic conditions do experience health insurance discrimination [Alper et al., 1994; Geller et al., 1996; Lapham et al., 1996].

Several state and federal laws prohibit the use of health information generally, or genetic information specifically, to discriminate in providing insurance coverage. At the federal level, the Americans with Disabilities Act proscribes discrimination against persons with disabilities which includes those with genetically related conditions. One important legislative change since the time data were collected for this study is the Health Insurance Portability and Accountability Act of 1996 (HIPAA). HIPAA, which was implemented in 2000, expressly forbids a group health insurance plan from using “genetic information” to establish rules for eligibility or continued eligibility in a health insurance plan [Gostin, 2001]. It also prohibits insurance companies from treating genetic information as a “preexisting condition in the absence of the diagnosis of the condition related to such information” [Gostin, 2001]. Thus, an individual cannot be denied health care coverage for a medical condition merely because they have a genetic marker for the condition, if they are asymptomatic. Importantly, however, individuals can be denied if they have symptoms of genetic disease. As such, HIPAA provides no protection for the vast majority of respondents in this study.

Further, these genetic-specific laws at the federal and state level are based on the assumption that genetic information is inherently different from other medical information. It has been argued that since an individual's genetic make-up is not under his or her personal control, he or she should not be discriminated against as a result of a genetic test [Raithatha and Smith, 2004]. Moreover, it has been argued that it is not appropriate to deny access to individuals merely *at-risk* for developing disease, when disease may not ever develop in the future. Indeed, like with HIPAA, most of the state genetics laws limit discrimination based on genetic risks or traits, rather than on actual genetic disease.

In fact, many authors reject 'genetic exceptionalism' arguments altogether and state that if it is wrong to use genetic information to discriminate, stigmatize, or limit access to insurance, it also should be wrong to use other medical information for the same purposes [Green and Botkin, 2003]. That individuals in this study with both genetic and non-genetic conditions experienced difficulties and had concerns regarding access to health insurance coverage suggests that future policy proposals should be broad-based and address the needs and concerns not only of those with obviously genetic conditions but those with other types of medical conditions as well.

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TABLE I

Demographic Characteristics of Respondents by Medical Condition

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Number	102	99	104	100	50	45	47	50	597
Relationship to self (%)**									
Affected adult	34.3	36.4	61.5	100	100	0.00	100	0.00	55.6
Parent	65.7	63.6	38.5	0.00	0.00	0.00	0.00	0.00	28.5
At-risk	0.00	0.00	0.00	0.00	0.00	100.0	0.00	100.0	15.9
Age category (%)**									
<40 years old	55.5	63.3	24.5	25.0	8.00	42.2	4.35	10.2	33.5
40-49 years old	33.7	28.6	36.3	56.0	22.0	22.2	13.0	24.5	32.8
50+ years old	10.9	8.16	39.2	19.0	70.0	35.6	82.6	65.3	33.7
Sex (%)**									
Male	22.6	15.2	29.8	56.0	0.00	0.00	42.6	38.0	27.5
Female	77.5	84.9	70.2	44.0	100	100	57.5	62.0	72.5
Marital status (%)**									
Married/partnered	76.0	42.9	82.7	36.0	68.0	82.2	84.8	84.0	66.1
Divorced/separated	11.0	21.4	9.62	28.0	24.0	13.3	15.2	6.00	16.5
Widowed	1.00	2.04	1.92	7.00	2.00	0.00	0.00	2.00	2.36
Other	12.0	33.7	5.77	29.0	6.00	4.44	0.00	8.00	15.0
Race (%)**									
African-American	7.92	91.9	13.6	69.0	14.0	6.67	6.38	0.00	32.8
White	86.1	4.04	81.6	25.0	82.0	91.1	91.5	94.0	62.5
Other	5.94	4.04	4.85	6.00	4.00	2.22	2.13	6.00	4.71
Education level (%)**									
Less than high school	0.99	6.06	6.80	26.0	0.00	0.00	6.38	4.08	7.58
High school degree	28.7	37.4	18.5	24.0	34.0	13.3	23.4	12.2	25.1
Some college/degree	55.5	46.5	40.8	36.0	44.0	60.0	36.2	49.0	45.5
Graduate school+	14.9	10.1	34.0	14.0	22.0	26.7	34.0	34.7	21.9

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Income (%) **									
<\$20,000/year	17.7	48.4	12.8	60.6	8.33	2.50	7.14	2.13	25.6
\$20,000-\$60,000/ year	38.5	36.6	27.7	30.3	39.6	35.0	28.6	27.7	33.1
>\$60,000/year	43.8	15.1	59.6	9.09	52.1	62.5	64.3	70.2	41.3
Employment status (%) **									
Full-time employed	54.0	39.4	53.5	23.7	66.0	73.3	52.2	67.4	50.1
Part-time employed	19.0	19.2	18.8	15.1	20.0	17.8	10.9	6.12	16.6
Unemployed	27.0	41.4	27.7	61.3	14.0	8.89	37.0	26.5	33.3

Generally, fewer than 2% of respondents had missing values for demographics. The exception was income, for which 6.4% of responses were missing. Those with HIV had the lowest percentage of missing values (2.6%), and those with diabetes had the highest (26.3%). Note that percentages may not sum to 100% due to rounding.

BC, breast cancer; CC, colon cancer.

** Overall χ^2 , $P < 0.001$.

TABLE II

Experiences With Health Insurance by Disease Group

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Number	102	99	104	100	50	45	47	50	597
Do you have health insurance? **									
Yes	96.0	96.0	100.0	80.0	98.0	97.8	100.0	100.0	95.0
No	4.0	4.0	0.0	20.0	2.0	2.2	0.0	0.0	5.0
What type of insurance is this? **									
Managed care	11.3	2.13	2.88	2.50	18.4	13.6	17.0	22.5	9.22
HMO	21.7	28.7	21.2	13.8	32.7	40.9	19.2	34.7	25.0
Fee-for-service	30.9	10.6	43.3	16.3	36.7	36.4	42.6	32.7	29.8
Medicaid/medical assistance	13.4	40.4	10.6	36.3	0.00	0.00	0.00	0.00	16.1
Medicare	2.06	6.38	6.73	20.0	0.00	2.27	10.6	4.08	6.91
VA	0.00	0.00	0.00	6.25	0.00	0.00	0.00	0.00	0.89
Some private insurance	12.4	3.19	7.69	1.25	10.2	2.27	6.38	2.04	6.03
Some public insurance	4.12	5.32	5.77	3.75	0.00	0.00	4.26	0.00	3.55
Other	4.12	3.19	1.92	0.00	2.04	4.55	0.00	4.08	2.48
Through whom do you get this plan? **									
Employer	52.6	54.0	51.3	100.0	66.0	46.5	70.3	68.8	59.4
Spouse's employer	37.2	25.0	42.5	0.00	25.5	39.5	24.3	22.9	30.8
Parents	5.13	4.55	3.75	0.00	0.00	4.65	0.00	2.08	3.01
Individual policy	1.28	2.27	1.25	0.00	8.51	6.98	5.41	6.25	3.76
Other	3.85	13.6	1.25	0.00	0.00	2.33	0.00	0.00	2.76
At the time you obtained coverage, did you have a choice of plans? **									
Yes	61.1	45.9	72.7	47.8	76.6	63.4	76.7	69.6	62.7
No	38.9	54.1	27.3	52.2	23.4	36.6	23.3	30.4	37.3
Did you get this coverage before or after you found out about your condition? **									
Before	29.5	39.8	45.1	33.8	55.1	34.9	58.7	30.0	39.4

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
After	70.5	60.2	54.9	66.2	44.9	65.1	41.3	70.0	60.6
Did you try to get more coverage when you found out? **									
Yes	25.0	16.7	11.3	19.7	6.1	0.00	2.3	2.0	12.4
No	75.0	83.3	88.7	80.3	93.9	100	97.7	98.0	87.6
Were you able to? **									
Yes	60.0	54.6	77.8	84.6	50.0	N/A	50.0	100.0	67.2
No	40.0	45.4	22.2	15.4	50.0	N/A	50.0	0.00	32.8

Missing, don't know, N/A, and refused answers were not included in these calculations.

BC, breast cancer; CC, colon cancer.

** Overall χ^2 , $P < 0.001$.

TABLE III

Qualitative Responses to Participants' Experiences and Future Worries With Health Insurance Coverage

Participants' experiences with health insurance coverage	
<ul style="list-style-type: none"> • "Usually if I get to questions that they want to know I just chuck the whole thing. Like if I wanted to apply for health insurance and they asked specifically, have you, are you HIV-positive, have you ever been tested, that kind of thing. Then I just don't, I don't apply. I don't even bother with it because I know that I'm not going to get it [health insurance]." [HIV AA] • "Quite frankly I talk to insurance people probably on a daily basis and I've had them, even my own insurance, admit to me that they raised my rates because I, I use the insurance and it—what I use it for is very expensive." [CF P] • "I make a lot less money because I . . . I work the job that I have for insurance coverage. . . and it's a lot less money but the main reason that I keep that job is, at least for [health insurance coverage]." [SCD-P] 	
Participants' worries about health insurance coverage	
Access to insurance	<p>"Well, my fear is, of course, being sick, losing my job, and not having medical coverage as a result of it. 'Cause I could never get medical coverage without employment." [BC affected]</p> <p>"I worry about having to find new health insurance and being denied." [Diabetes AA]</p>
Coverage of all medical needs	<p>"I worry about um, yeah, the medical coverage that I have not covering all of my durable goods expenses, between all the insulin, the syringes, the test strips, and it's a pretty high cost that right now I don't have to pay for." [Diabetes AA]</p> <p>"I worry that the insurance companies will find legal ways to just limit my coverage to such small amounts that it's insufficient." [BC AA]</p> <p>"I worry about not getting the same degree of care, like if I lost my job and had to get different health insurance. . . different insurance policies treat you different and it's all what your insurance company is willing to pay, how good of care you get." [CC AA]</p> <p>"The main thing I worry about, they're doing a lot of cutbacks, welfare and medical assistance and my main concern is not having any kind of medical insurance. Not being able to afford my medicines whenever I need medical care and not being able to get it. Because I'm, you know, I'm on disability. I'm not gonna be able to pay for it. You know, some of my medicines I'm on at least 27 pills a day which is 15 different medicines. I'm not gonna be able to buy that, pay for it." [HIV AA]</p>
Worries regarding children's future access to insurance	<p>"Our major worry is once our daughters are old enough that they are no longer covered by our own health insurance, after they have reached age twenty-three and have completed their college studies, that they will have trouble obtaining health insurance coverage." [CF P]</p> <p>"Well her father has her covered until she's eighteen. I worry that I can't afford to pay for her medical expenses or insurance to cover them after she is eighteen. I worry that when she's on her own she won't be able to afford her medical expenses or insurance to cover them. Um, that she might be denied by an employer." [CF P]</p> <p>"I worry that my daughter when she is no longer covered under my policy she will always have to have a job that provides benefits or she'll be paying an exorbitant amount of money for health care benefits because she has, she always has to have health care benefits." [DM-P]</p> <p>"I worry that he will not be able to get health insurance when he's old enough to work and that there will be a lifetime maximum that he'll cap out." [SCD P]</p> <p>"I'm really afraid that my children are going to have difficulty getting affordable insurance because of the family risk of colon cancer." [CC AR]</p>
Fears regarding genetic testing	<p>"Well, I think it's definitely a worry that you won't get covered because, you know, you're at risk and I think that at this time and age anyone can get any information, I can't say that they can't, I just can't say that no one can get my information because I'm sure they can." [BC AR]</p> <p>"I'm really just making decisions not to do the genetic testing at all and not having a record of anything like that I think is important at this point since there aren't any, you know, laws in writing about what the insurance gets and how they can get it, that makes me uncomfortable." [BC AR]</p> <p>"I would not be tested for any genes for the fact that someone can use it and I wouldn't be covered for it." [CC AR]</p> <p>"I guess I would say I am concerned about the privacy of the tests and that was one of the things that if I do go through with them. . . I would want to know a lot more about how to handle those records because I would be concerned that it would get in the wrong hands if not. I would just want to make sure that if I changed insurance companies that information wouldn't be made a part of my record. Um, because I wouldn't want it to interfere. I would want to make sure that if I get a genetic test that it would be kept absolutely confidential." [CC AR]</p> <p>"We decided not to genetically test our two daughters for having the cystic fibrosis gene, mostly because we just felt like we didn't know what would happen in the future. Would that be, you know if it was known that they're carrier, would an insurance company say we won't cover you having a baby because you're taking a risk or something. So we opted to just not, rather not know." [CF P]</p>

AA, affected adult; P, parent; AR, at-risk.

TABLE IV
Attitudes and Beliefs Regarding Health Insurance and Confidentiality, by Medical Condition

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Number	102	99	104	100	50	45	47	50	597
Most people in society have little power to stop health insurance companies from getting medical information about them.									
Agree	67.7	57.6	64.7	61.6	63.3	68.9	73.9	62.5	64.2
Neutral	24.5	21.2	24.5	23.2	20.4	15.6	15.2	20.8	21.7
Disagree	7.8	21.2	10.8	15.2	16.3	15.6	10.9	16.7	14.1
People can pick which parts of their medical histories insurance companies can get.*									
Agree	24.5	40.2	22.6	27.2	22.5	33.3	25.5	16.3	27.1
Neutral	15.7	19.6	14.7	25.3	16.3	24.4	21.3	18.4	19.2
Disagree	59.8	40.2	62.8	47.5	61.2	42.2	53.2	65.3	53.7
Most people would be upset if they knew all the ways health insurance companies use information about them.									
Agree	69.0	68.4	63.7	67.7	68.0	71.1	60.9	72.9	67.5
Neutral	26.0	19.4	29.4	20.2	20.0	17.8	28.3	18.8	23.0
Disagree	5.0	12.2	6.9	12.1	12.0	11.1	10.9	8.3	9.5
Health insurance companies do not share with one another medical information about the people they cover.*									
Agree	14.3	31.6	11.9	24.5	6.4	11.1	20.0	10.4	17.7
Neutral	32.7	19.0	23.8	27.6	31.9	31.1	20.0	35.4	27.0
Disagree	53.1	49.5	64.4	48.0	61.7	57.8	60.0	54.2	55.3
If you ask your healthcare provider not to send specific test results to health insurance companies, s/he will do as you ask.**									
Agree	56.3	52.6	39.2	68.0	28.6	50.0	35.6	42.6	49.1
Neutral	24.0	22.7	30.4	15.5	42.9	29.6	26.7	27.7	26.0
Disagree	19.8	24.7	30.4	16.5	28.6	20.5	37.8	29.8	25.0
It is against the law for my doctors to give medical information to a health insurance company without my permission.									
Agree	72.0	73.5	75.8	75.5	55.1	75.6	72.7	60.4	71.4
Neutral	18.0	17.4	16.2	17.4	18.4	15.6	22.7	29.2	18.6
Disagree	10.0	9.2	8.1	7.1	26.5	8.9	4.6	10.4	10.0
Doctors should be punished if they release medical information about patients to health insurance companies without permission.*									
Agree	73.5	72.7	69.6	76.0	62.5	82.2	66.0	81.6	73.0
Neutral	14.7	9.1	18.6	10.4	10.4	13.3	21.3	14.3	13.8

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Disagree	11.8	18.2	11.8	13.5	27.1	4.4	12.8	4.1	13.3

Missing, don't know, N/A, and refused answers were not included in these calculations.

BC, breast cancer; CC, colon cancer.

* Overall χ^2 , $P < 0.05$.

** Overall χ^2 , $P < 0.001$.

TABLE V
Percentage of Respondents Reporting Health Insurance Discrimination by Medical Condition

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Number	102	99	104	100	50	45	47	50	597
Have you ever been denied health insurance or offered it at a prohibitive rate? **									
Yes	42.1	32.7	25.0	23.4	30.0	15.6	17.0	12.2	26.8
No	57.9	67.4	75.0	76.6	70.0	84.4	83.0	87.8	73.2
Do you think your health insurance rates were ever raised specifically because of your medical history?									
Yes	14.1	6.7	10.0	0.00	6.7	5.7	5.4	4.3	8.1
No	85.9	93.3	90.0	100.0	93.3	94.3	94.6	95.7	91.9
Have you ever had a health insurance company limit your coverage for care related to your condition while still covering other problems? *									
Yes	29.8	17.1	19.3	12.0	22.9	10.0	8.9	6.3	17.6
No	70.2	82.9	80.7	88.0	77.1	90.0	93.7	93.7	82.4
Have you ever refused to give a health insurance company access to records or refused to answer specific questions? *									
Yes	3.4	2.2	3.4	8.8	4.2	0.00	2.1	2.0	3.0
No	96.6	97.8	96.6	91.2	95.8	100	97.9	98.0	97.0
Have you ever decided not to use health insurance to pay for treatment? *									
Yes	6.9	0.00	4.1	17.7	8.1	10.0	2.6	2.3	5.5
No	93.1	100	95.9	82.3	91.9	90.0	97.4	97.7	94.5

Missing, don't know, N/A, and refused answers were not included in these calculations.

BC, breast cancer; CC, colon cancer.

* Overall χ^2 , $P < 0.05$.

** Overall χ^2 , $P < 0.001$.

TABLE VI
Perceptions of the Likelihood of Future Risks Associated With Health Insurance by Medical Condition

	CF	SCD	Diabetes	HIV	BC affected	BC at-risk	CC affected	CC at-risk	Total
Number	102	99	104	100	50	45	47	50	597
What is the chance that a health insurance company could obtain medical information about you without your knowledge?									
Likely	73.3	58.2	72.0	63.6	85.4	75.0	77.3	71.1	70.5
Not sure	10.0	14.3	14.0	14.3	6.3	11.4	13.6	8.9	12.1
Unlikely	16.7	27.5	14.0	22.1	8.3	13.6	9.1	20.0	17.4
What is the chance that a health insurance company could obtain medical information about you without your permission?*									
Likely	62.4	53.8	59.4	59.7	71.7	54.6	65.2	51.1	59.4
Not sure	9.7	10.8	19.8	14.3	4.4	25.0	17.4	8.5	13.7
Unlikely	28.0	35.5	20.8	26.0	23.9	20.5	17.4	40.4	26.9
What is the chance that your health insurance company could get medical information about you from some computerized record without you even knowing? **									
Low chance	13.9	21.2	9.9	15.8	4.1	6.8	0.00	14.0	12.3
Medium chance	19.8	24.2	15.8	33.7	12.2	15.9	15.2	20.0	20.9
High chance	66.3	54.6	74.3	50.5	83.7	77.3	84.8	66.0	66.8
What is the chance that if you had to change insurance plans, the new one would not cover all of your medical needs? **									
Low chance	19.0	41.6	22.2	32.9	40.9	32.6	35.6	52.2	32.4
Medium chance	22.1	24.7	29.3	24.7	18.2	39.5	13.3	21.7	24.5
High chance	59.0	33.7	48.5	42.4	40.9	27.9	51.1	26.1	43.0
What is the chance that in the future you will be denied health insurance or that your health insurance will become unaffordable?									
Low chance	22.1	39.8	34.7	43.3	43.8	30.2	32.6	40.8	35.6
Medium chance	28.4	24.7	29.7	23.3	22.9	32.6	34.8	20.4	26.9
High chance	49.5	35.5	35.6	33.3	33.3	37.2	32.6	38.8	37.5

Missing, don't know, N/A, and refused answers were not included in these calculations.

BC, breast cancer; CC, colon cancer.

* Overall χ^2 , $P < 0.05$.

** Overall χ^2 , $P < 0.001$.