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Medical Privacy and the Disclosure of Personal Medical Information: The Beliefs and Experiences of Those with Genetic and Other Clinical Conditions

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Abstract

There has been heightened legislative attention to medical privacy and to protections from genetic discrimination, without large-scale studies to document privacy concerns or analysis of whether experiences differ by whether the condition is genetic (defined here as a single-gene disorder) or non-genetic. To determine whether experiences regarding privacy, disclosure, and consequences of disclosure differ by whether one's medical condition is genetic, we conducted a descriptive study with one-time, structured quantitative and qualitative interviews. We interviewed approximately 100 adults or parents of children with each of the following medical conditions: sickle cell disease, cystic fibrosis, diabetes, and HIV, and 200 adults with or at risk for breast cancer or colon cancer. The percentages of the total 597 respondents experiencing positive or negative consequences of disclosure and the degree to which experiences differed by whether the condition was genetic were the outcomes of interest. Seventy-four percent were glad and 13% regretted others knew about their condition; these findings did not differ significantly by genetic vs. non-genetic condition. Reports of job and health insurance discrimination were not uncommon for the overall study population (19 and 27%, respectively) but were more likely among those with genetic conditions (30 and 37%, respectively). Legislation and other policymaking should target the needs of persons with all conditions and not focus exclusively on genetic discrimination, given that experiences and concerns generally do not differ based on the genetic etiology of the condition.

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Keywords

confidentiality; disclosure; family members; hereditary disease; cross sectional survey

Introduction

Medical privacy is an important topic in health policy debates [Gostin, 1995b]. Current technologies, with easily shared electronic records, computer-based insurance files, and highly integrated electronic communication networks, have made the transfer of confidential information almost effortless. Furthermore, the possibility of predicting future, in addition to existing, health problems through genetically based tests has heightened privacy concerns. Many commentators have warned of potential privacy violations or breaches of confidentiality [Natowicz et al., 1992; Kass, 1993; Gostin, 1995a; Orentlicher, 1997] and many have proposed remedies [NIH-DOE, 1993; Rothenberg et al., 1997; Gostin and Hodge, 2002]. State and federal legislators have considered measures to limit the types of medical information that can be released and under what conditions.

Recently, the U.S. Department of Health and Human Services promulgated the first national health informational privacy regulations in the United States, authorized by the Health Insurance Portability and Accountability Act of 1996. Full compliance is required by 14 April 2003 (66 Fed. Reg 2001). Under the rules, health care providers must obtain patient authorization for the use and disclosure of individually identifiable information for most purposes [Gostin, 2001]. Much state and local medical privacy law exists, but safeguards have been characterized as inadequate and highly variable [Workgroup for Electronic Data Interchange, 1992; Gostin et al., 1996; Institute for Health Care Research and Policy, 1999]. Genetic nondiscrimination in employment laws is in place in 23 states, and 34 states forbid genetic discrimination in underwriting individual policies and ban genetic information in rate-setting for individuals and groups.

Despite significant legislative activity and scholarly analysis, few studies document experiences and values concerning medical privacy of individuals with chronic medical conditions. An early study of genetic discrimination reported 41 case histories of potential genetic discrimination, generally related to insurance or employment [Billings et al., 1992]. Other studies document life or health insurance refusal or job discrimination due to genetic conditions [Geller et al., 1996; Lapham et al., 1996] while another notes genetic discrimination occurred in contexts beyond insurance or employment [Low et al., 1998]. Surveys also document discrimination based on HIV [Gostin, 1990; Levin et al., 1991; Kass et al., 1992] or associated characteristics [Kelly et al., 1987; Schwartzbaum et al., 1990]. Public opinion polls have examined citizens' views about privacy generally. An Equifax survey found 65% of the public feels “protecting the privacy of consumer information” is very important, and 24% feel they have been the victim of “an improper invasion of privacy” [Louis Harris & Associates, 1996]. A Gallup poll revealed “an overwhelming majority of Americans (78%) do not want the government or other third parties to have access to their medical records—including genetic information—without their permission” [The Gallup Organization, 2000].

While studies reveal that privacy is valued by the public, and incidents of genetic and other discrimination have been reported, no large-scale studies have compared the experiences of those with genetic conditions to those of persons with other conditions. Since much privacy legislation has focused on genetic discrimination, [Annas et al., 1995] it is important to document whether experiences of persons with genetic conditions differ from those of persons with other conditions.

Subjects and Methods

Study Sample

Participants were enrolled from March 1996 until February 2000. Initially, 100 respondents were sought from each of four groups: adults (age 18–64) or parents of children with cystic fibrosis (CF), sickle cell disease (SCD), and diabetes, and adults with HIV infection. In October 1997, we added 50 individuals with a personal and 50 with a family history of breast cancer, and another 50 of each with colon cancer. Respondents were recruited from clinics or research studies of the Johns Hopkins Medical Institutions, from disease registries in Maryland, and from advertisements. This protocol was approved by IRBs from the Johns Hopkins Medical Institutions and the State of Maryland. We use the term “affected adults” to mean adult respondents with the condition, “parents” to mean respondents with a child with the medical condition, and “at risk adults” to mean respondents with a family, but not personal, history of cancer. The conditions referred to as “genetic” are the single-gene disorders, CF and SCD.

A total of 602 individuals completed interviews. Three were excluded from quantitative analysis because participants were over 64, and two others due to incomplete data. Problems with audiotapes and exclusion of interviews in Spanish resulted in 541 tapes for qualitative analysis. Study demographics are in Table I.

The Interview

One structured interview was administered by a trained interviewer to each participant, either in person (50%) or by phone (50%). Written informed consent was obtained from those interviewed in person; oral consent was obtained for telephone interviews. Interviews lasted approximately 45min, and participants were compensated $20 plus travel expenses. The interview included quantitative and qualitative items regarding knowledge, attitudes, and experiences with privacy and disclosure, confidentiality and discrimination, employment, health and life insurance, and demographics. Data are reported here related to privacy, disclosure, and consequences of disclosure.

Analysis

Quantitative—Responses to survey questions were cross-tabulated with demographic variables, and Pearson's chisquare test for independence was performed on these contingency tables. Logistic and ordinal logistic regression (proportional odds) analyses were performed with question responses as outcomes and demographic variables as predictors.

Qualitative—Electronic transcripts of open-ended responses were imported into QSR NUD.IST 4.0 for qualitative analysis [Qualitative Solutions and Research Pt. Ltd, 1997]. Responses were labeled with index codes by several trained coders, with inter-coder reliability checked and monitored. Printouts corresponding to index codes were sub-coded, and patterns and differences across study populations identified.

Results

Privacy and Disclosure

Approximately one-third of respondents considered themselves private, another third considered themselves “neutral,” and another third “open” (Table II). Men were more likely than women to call themselves private (42 vs. 28%, overall χ^2, P=0.007), and affected adults more likely than parents to call themselves private (36 vs. 23%, overall χ^2, P=0.081). In ordinal logistic regression, those with HIV and those with or at risk for colon cancer were more likely than those with CF to call themselves private. African-Americans were nearly twice as likely as whites to say they were private. Whether participants had a “genetic condition” (according to our definition) was not significantly related to whether they called themselves private.

Respondents were asked who else knew about their medical condition (Table II). Ninety-seven percent of married respondents and 99% with partners said their spouse or partner knew; 84% percent said their children knew, although only 53% of those with children five and under (χ^2 test, $P<0.001$) said children knew. The 47% who said all friends and neighbors knew were more likely to be white (OR=1.90, P=0.045) and to call themselves neutral (OR=1.70, P=0.020) or open (OR=2.31, $P<0.001$). Persons with HIV were least likely in all items to say others knew about their condition, and women generally were more likely than men to say others knew. The likelihood of others knowing did not differ by whether respondents had a genetic condition.

Seven percent reported having been pressured by a health care provider to disclose their condition to others. Affected adults were more likely than parents to report having been pressured by doctors (9 vs. 4%, P=0.054). Six percent overall (20% for HIV; $P<0.001$) had not disclosed their medical condition to at least one medical provider, and 5% said they had not reported a medical claim to a health insurance company because the company would learn about their condition. Those with genetic conditions were no more likely to report this.

Consequences of Disclosure

Glad others know—Overall, 74% said they were glad others know about their condition (Table III). The percentage of respondents saying they were glad did not differ significantly by disease group (including by whether the condition was genetic) nor by demographics.[1]

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[1] This question was added after the study had been initiated, by which time approximately half of the participants with HIV had been enrolled. There is a trend in existing data for those with HIV to be more glad others knew, but with the smaller numbers, it does not reach statistical significance.

The primary qualitative response to why they were glad others knew, and voiced by respondents in all sub-samples, was that they received emotional support (Table IV, online version, supplement material). Several respondents with SCD, CF, or, in particular with diabetes B conditions where individuals can experience sudden health changes B reported feeling reassured others knew, in case something should happen. Moreover, participants from these three subsamples voiced that others better understand their behavior—such as a need to not come to work or to eat suddenly—when they know.

Some respondents—especially those with breast cancer— said being open meant they could learn from others with the same condition, or it led them to get information. One woman described a deep sisterhood between herself and another woman at work with the disease and another felt she had been “initiated into a club.” Others described disclosure resulting in their learning of others with the condition leading “normal lives.” Several respondents mentioned that being open resulted in others having fewer misconceptions about their condition (Table IV), while a few said that the more others knew, the more quickly a cure would be found. Persons with CF were virtually unique in reporting that being open allowed for important fund raising for the condition.

Finally, many participants mentioned that being open led others to undergo screening themselves. This reason was mentioned overwhelmingly by respondents with breast or colon cancer, by two participants with SCD, and by one with HIV. Thirteen women independently mentioned that having breast cancer led others, they believed, to getting mammograms. It was poignant also to hear women speak of their daughters and sisters now being more conscientious about getting mammograms and doing breast exams. Nine respondents with colon cancer, similarly, described this, saying they hoped family members would take precautions. One man stated that everyone in his family got tested, and one sister learned she had the disease. This was never mentioned by those with CF or diabetes.

Regret others know—Thirteen percent said they regret others know about their condition (Table III). Affected adults were significantly more likely than parents to regret others know (17 vs. 7%; overall χ^2, P=0.008), and African-American respondents were more likely to regret others know than white respondents (18 vs. 10%; overall χ^2, P=0.100). In logistic regression, those with HIV were significantly more likely to regret others knowing than those with CF (Table V), and those of middle income were more likely to regret than those of lower income. Adults were significantly more likely to regret others knowing than were parents (OR=7.14, $P<0.001$; data not shown). Having a genetic condition was not predictive of regretting others knew. Overall, 8.9% of the sample reported both regretting and being glad others know.

The main reason respondents in all groups regretted others knowing was that they were treated differently. Sometimes they were pitied, sometimes friends or family became over-protective, and sometimes they were stigmatized. Table IV provides further examples of responses (Table IV). While most qualitative reasons for regretting others knew related to reactions from family, friends, or coworkers, four respondents described regretting others knew because it led to being fired, and two respondents with HIV described being denied medical care.

Hope others will not find out—Eighteen percent overall hoped others would not find out about their medical condition (Table III). In regression analysis (Table V), those at risk for breast cancer, of middle income, single, and who call themselves private or neutral, were significantly more likely to hope others would not find out. Related, 18% believed there was a high chance that others in their social crowd would treat them differently if they found out. Having a genetic condition was not predictive of either of these findings.

Respondents' worries about others finding out centered mostly on interpersonal situations, with some also fearing diminished access to desired opportunities (Table IV). Some parents admitted that, while they were open about their child's condition now, they might be less open when the child got older.

Persons with HIV, breast or colon cancer often were protective of others in their family, fearing disclosure might hurt or upset them. Six respondents with HIV worried about this (Table IV). Five women with breast cancer described not wanting their older parents to worry, particularly since four had had another family member die of the disease.

At least one respondent in each disease group worried about others finding out in relation to their employment. Some said they wait to tell future employers until they secure the job since “they may discriminate.” No one with SCD, diabetes, or HIV volunteered, in qualitative responses, worrying about insurance, while four respondents with CF, four with colon cancer, five at risk for colon cancer, seven with breast cancer, and seven at risk for breast cancer worried that others finding out might restrict access to health or life insurance. Three respondents with diabetes voiced a fear of losing driver's licenses; one specifically said he lied when asked about a history of diabetes.

Finally, many respondents simply described valuing privacy for its own sake. Some respondents described carving out small niches in their lives where no one knew. Others, like this adult with CF, simply said, “It's none of their business.” Several persons with HIV made comments that others do not need to know. No one with diabetes expressed a desire to keep their condition private for its own sake.

Insurance, and Employment, and Discrimination

Overall, 52% said they would not care who got medical information about them if everyone could get good health insurance, and 40% would not care if it could not affect their job (Table VI). Respondents who still cared about privacy, even if everyone could get good insurance, were more likely to have HIV, to have a family rather than personal history of breast cancer, to be younger, and to call themselves “private.” Those who still cared about privacy, even if disclosure could not affect their job, were more likely to have HIV or a family history of breast cancer.

Nineteen percent of respondents (42% of those with SCD, overall χ^2, $P<0.001$) reported not being hired for a job due to their medical condition (Table VII). Thirteen percent (32% of those with HIV, overall χ^2, $P<0.001$) reported not applying for a job because they feared being asked about their medical condition. Twenty-seven percent reported being denied health insurance or offered insurance at a rate too expensive to afford (42% among those with CF, overall χ^2, $P<0.001$). Inregression analysis, those with genetic conditions (CF and SCD) were more likely to report having been denied health insurance and having not been hired for a job because of their medical condition (Table VIII).

Discussion

In this sample of approximately 600 persons with chronic medical conditions, almost everyone had told their spouse/partner about their condition, while significantly fewer had told all of their friends and neighbors. Respondents with HIV were consistently most likely to keep information private. Parents generally were more open about their children's medical condition than affected adults were about themselves, and women tended to be more open than men.

The vast majority of respondents were glad others knew about their condition. Respondents reported receiving emotional support from others who knew, and some were glad others knew in case a health problem should occur. Thirteen percent regretted others knew. While generally this was because others had shunned them, become overprotective, or treated them differently, 19% reported job discrimination, and 27% reported being denied health insurance or offered insurance at a prohibitive rate. Eighteen percent believed there was a high chance that others in their social crowd would treat them differently if they found out, and 13% had decided not to apply for a job because they were afraid they would be asked about their or their child's condition.

One of the striking findings was the lack of systematic differences based on whether the respondent had a genetic condition vs. one of different etiology. To further test this conclusion, we also conducted our analyses, redefining “genetic disease” to include not only those with SCD and CF, but to include participants in the affected and at risk cancer groups, as well. This regrouping still did not result in those with genetic conditions answering questions differently (data not shown) from those without genetic conditions. On the contrary, some findings may be generalizable to anyone with a chronic condition—such as disclosing to others only after getting to know them, worrying others will find out, and worrying others might treat one differently if they know about the condition. Results that varied by disease group generally did not differ by genetic versus nongenetic but, rather, based on characteristics of the condition (such as how stigmatizing it is) or by demographic characteristics of the respondents.

Given that findings generally did not differ by the genetic etiology of the condition, it was striking that, while job and health insurance discrimination were reported by some proportion of every disease subgroup, those with genetic conditions were significantly more likely to report these problems. And despite this, those with genetic conditions were no more concerned about others finding out than the other groups, nor were they any more likely to be private. As described below, a limitation of this study is that all data, including reports of discrimination, were self-reported. Thus, we are unable to know with certainty whether more instances of discrimination were experienced by those with genetic conditions, or whether, when an employment or insurance rejection occurred, these participants were more sensitive to the possibility of disease-based discrimination, given that genetic counseling sessions and legislation both have stressed that discrimination might exist for those with genetic conditions. Indeed, there is some evidence that genetic counselors have heightened concerns about genetic discrimination, and they may be likely to pass those concerns on to their clients [Matloff et al., 2000]. Our interviewers asked respondents to produce documentation for every reported instance of discrimination, but respondents generally had little hard evidence. Indeed, it would be completely expected that rejections generally would not be framed as being related to the individual's medical condition, regardless of the true, underlying reason. It also is conceivable that individuals in all groups may have altered their lives to prevent anticipated discrimination and/or stigma [Geller et al., 1996].

There are other limitations to this study as well. First, this was predominantly a local sample. To the degree that experiences about privacy or willingness to disclose are influenced by one's care providers, the generalizability of findings may be further limited. A final limitation is that, although our study involved detailed interviews of nearly 600 interviews from eight study populations, the two single-gene disorder groups and six other groups are not completely representative of genetic and non-genetic populations, respectively.

This study builds on existing literature regarding genetic discrimination in two respects: while other studies have examined genetic discrimination, this study analyzed whether the likelihood of adverse experiences was greater among those with genetic versus other conditions. We noted that the positive and negative effects of disclosure do not generally differ between persons with genetic versus other medical conditions. Second, few studies have examined the effect of disease disclosure on interpersonal relationships. While experiences with health insurance, life insurance, and/or employment were crucially important to respondents, the effects of disclosure on their relationships with family, friends, neighbors, and parents of their children's friends were at least as salient. Participants stressed the importance of controlling information themselves and disclosing information only when they wanted. These findings suggest that future policy proposals relating to medical privacy should be broad-based and address the needs and concerns of those with both genetic and other medical conditions.

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Table I

Demographic Characteristics of Respondents, by Medical Condition

	CF	SCD	Diabetes	HIV HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
[a] 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	15.9
[a] 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
[a] 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
[a] 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
[a] 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
[a] 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
[a] Income (%)									

	CF	SCD	Diabetes	HIV HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
<$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
[a] 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%). BC, breast cancer; CC, colon cancer.

[a] Overall χ^2, $P<0.001$.

TABLE II

Self-Related Privacy Level, and Percentage of Other Parties who Know About Respondent=s Medical Condition, by Medical Condition

	CF	**SCD**	**Diabetes**	**HIV**	**BC affected**	**BC at risk**	**CC affected**	**CC at risk**	**Total**
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
[a] How would you rate how private you are?									
Private	19.0	32.6	29.4	47.8	24.0	28.9	34.0	40.0	31.84
Neutral	32.0	45.3	28.4	32.6	36.0	33.3	34.0	32.0	34.25
Open	49.0	22.1	42.2	19.6	40.0	37.8	31.9	28.0	33.91
Do they know									
[a,b]Spouse/ex-spouse									
Yes	98.5	100	96.3	75.0	97.7	94.6	100	97.7	96.6
No	1.47	0.00	3.75	25.0	2.27	5.41	0.00	2.33	3.41
Partner/ex-partner									
Yes	100	100	100	96.8	100	100	100	100	98.6
No	0.00	0.00	0.00	3.23	0.00	0.00	0.00	0.00	1.39
[a] Children									
Yes	85.4	83.7	98.0	52.2	95.1	73.3	95.0	100	84.3
Some do/some do not	2.44	6.12	0.00	13.0	2.44	6.67	0.00	0.00	4.20
No	12.2	10.2	2.00	34.8	2.44	20.0	5.00	0.00	11.5
[a] Immediate family									
Yes	100	94.9	99.0	65.6	90.0	88.9	95.4	97.9	91.2
Some do/some do not	0.00	3.06	0.00	8.89	2.00	6.67	4.65	2.08	3.19
No	0.00	2.04	1.03	25.6	8.00	4.44	0.00	0.00	5.66
[a] Friends and neighbors									
Yes	54.4	28.9	63.3	20.8	74.0	48.8	59.1	34.0	46.6
Some do/some do not	41.3	57.7	29.6	52.0	26.0	44.2	29.6	52.0	42.5
No	4.35	13.4	7.14	27.3	0.00	6.98	11.4	14.0	10.9
[a] Employer									
Yes	86.7	74.1	91.1	51.6	91.7	50.0	87.5	41.9	74.4
No	13.3	25.9	8.93	48.4	8.33	50.0	12.5	58.1	25.6

	CF	SCD	Diabetes	HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
[a] Healthcare provider									
Yes	96.6	95.9	96.8	87.5	85.7	86.7	88.6	55.1	89.1
Some do/some do not	3.37	3.06	1.05	3.75	14.3	11.1	9.09	36.7	8.01
No	0.00	1.02	2.11	8.75	0.00	2.22	2.27	8.16	2.91
[a] Health insurance company									
Yes	92.7	92.9	94.3	80.7	95.8	46.9	90.2	45.0	84.5
No	7.32	7.06	5.68	19.4	4.17	53.1	9.76	55.0	15.5

BC, breast cancer; CC, colon cancer.

[a] Overall χ^2, $P<0.001$.

[b] Including only those who reported they were married, separated, or divorced.

TABLE III

Percentage of Respondents who Answered They Were Glad Others Knew, Regretted Others Knew, or Hoped Others Would not Find out, by Medical Condition

	CF	SCD	Diabetes	HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
Do you regret anyone finding out?									
Yes	73.9	69.2	76.5	78.4	76.0	84.4	76.1	62.0	12.6
No	26.1	30.9	23.5	21.6	24.0	15.6	23.9	38.0	25.9
[a] Are you glad someone found out?									
Yes	10.4	17.5	7.84	22.0	10.0	13.3	12.8	2.00	74.1
No	89.6	82.5	92.2	78.0	90.0	86.7	87.2	98.0	87.4
[b] Is there anyone you hope does not find out?									
Yes	13.8	7.53	11.1	30.7	22.0	34.1	22.2	14.0	17.9
No	86.2	92.5	88.9	69.3	78.0	65.9	77.8	86.0	82.1

BC, breast cancer; CC, colon cancer.

[a] Overall χ^2, $P<0.05$.

[b] Overall χ^2, $P<0.001$.

TABLE IV

Qualitative Responses to why Participants Are Glad Others Know, Regret Others Know, or Hope Others do not Find Out

Question	Reason
Do you regret anyone found out about your condition?	
CF	"People say, 'Oh, I'm sorry,' and I hate that comment… I mean, people are born with all different things, and she just happens to be born with that." [parent]
	"People that have children, normal, for lack of a better word. They kind of, I don't know, look at you like you're to be pitied, you know. And, uh if something arises or some kind of stress or something. They'll say she stressed because of her daughter. But you know, I'm not stressed at all because of my daughter. I'm stressed because you're an idiot!" [parent]
	"… [my coworker talks a lot] so I have to spend time reversing the stigma… she's really ignorant to the disease." [affected]
SCD	"It's like a pity thing… 'poor little fellow,' stuff like that. They didn't say it, but you can see it in their face." [parent]
	"Some friends and coworkers look at you different. Some felt sorry for me, some got distant." [affected]
	"… [my aunts and uncles] didn't want me to do this, they didn't want me to do that. And my parents were the same way…I wanted to be treated the same, and do what I was doing." [affected]
	"… [I regret that females know], you're half a man after that." [affected]
	"Some people would think it's contagious, you really find out who your friends are." [affected]
	"Once [employer] finds out, they think you're going to miss a lot of days, and they let you go." [affected]
	"They couldn't keep me on. They needed someone to come in every day, though it's a disease that you can't have much control over." [affected]
Diabetes	"Sometimes they all want to be 'mother" and worry 'Are you okay? Are you okay? Are you allowed to eat that"'? [affected]
HIV	"Well it has always been my experience that when I tell people, they burst into tears and then I feel sorry for them.… I get tired of when people ask me how long have I known I was positive. And I tell 'em it's been ten years and you know, the reaction I get from them, you should be dead by now and I get tired of that. I really get tired of that. I'm healthy, I'm—Why should I be dead now?"
	"Okay my family they cast me out, they don't want me around them and when I come over they have a special cup for me… My brother works around a hospital and he don't want me around his children or nothing because he is afraid I might pass the germ because you can cough or whatever and so when I come see him I stand outside and I talk to him… My mother passed and I didn't go to the funeral, I didn't go to the wake because I know what they are going to think, I caused my mother to die."
	"… [my friends] are no longer my friends."
	"I cook dinner, and [my wife] doesn't want to eat the same food."
BC affected	"[I wanted to tell my students to educate them] but then they would become very protective, and I'd resent that."
	"In a way, they'll look at you and all. I'm so distanced from everybody."
BC at risk	"It's not like HIV, I mean HIV has such a stigma, breast cancer, you know you don't ask for it, I'm not saying you ask for HIV, I better watch that one. I'm not saying you ask for HIV, nobody asks for it you know and you can get it through a transfusion, but uh, with breast cancer, it's such a genetics thing."
CC affected	"They didn't want me to pick something up or work extra hours or something like that."
	"[I regret] all of them [knowing], but what the hell are you going to do about it? I think it's rather embarrassing myself."
Are you glad anyone found out about your condition?	
CF	"Everyone knows what to do if they see her have difficulty breathing." [parent]
	"[People] understand why I cough, and that it's not contagious." [affected]
	"They understand. I've taught them, and they've watched a videotape." [affected]
	"We've taught teachers and health care professionals about the condition." [affected]

Question	Reason
	“Just talking about it helps me deal with it.” [parent]
	“[People] included us in their prayers.” [parent]
SCD	“Something could happen anytime, and I'm not always there.” [parent]
	“Friends at school knew what to do when I went into crisis.” [affected]
	“It's not like I died, I beat it.” [affected]
	“When my niece got pregnant, she had the test.” [affected]
	“[They] understand when I don't feel well.” [affected]
	“Coworkers know why I don't come in sometimes.” [affected]
Diabetes	“My daughter may need help; everyone must be able to intervene.” [parent]
	“… they have to know for his safety.” [parent]
	“… everyone at school keeps out an eye.” [parent]
	“… his classmates say, hey, you can't give him a candy bar.” [parent]
HIV	“A woman at head start realized she had to start protecting herself.”
BC affected	“Every time you share your story you may help someone else.”
	“I was the cause to have many women to go have mammograms. I am very proud of that fact.”
	“The more I talk about it, the more my friends get mammograms.”
	“People come out of the woodwork, and they're so nice.”
CC affected	“People always hear of people dying from cancer. It's nice for them to realize people can survive, too.”
	“I'm a survivor; It's important for everyone to know.”
Is there anyone you hope does not find out?	
CF	“[I want] future male friends… to know me first and see it doesn't control my life, I control it.” [affected]
	“Cystic fibrosis has changed a lot, and I don't want them to have the wrong perception.” [affected]
	“My child cannot get chicken pox. They're not very understanding of the letter after letter being sent out saying if your child has it, please notify the school.” [parent]
Diabetes	“It irritates me when people say, he'll outgrow it… People don't understand and tend to be insensitive.” [parent]
HIV	“[Don't want mother and family to know] because it will go from here to Canada and back!”
	“I hope my parents and grandmother never have to deal with it.”
	“My father, an aunt who is 88. I don't want to trouble them. As soon as you say you're HIV positive you have to say you're gay and they have to deal with both issues at once.”
BC affected	“My mother is 81. And knowing how they dealt with my sister…”
CC affected	“[My 15-year-old son has enough] life pressures… and one thing he doesn't need is more worry about whether his dad is going to keel over from colon cancer.”

BC, breast cancer; CC, colon cancer.

TABLE V

Odds Ratios for Whether Participants Regret, are Glad, or Hope Others do not Find Out

Covariate	Odds ratio		
	Do you regret others found out?	**Are you glad others found out?**	**Is there someone you hope does not find out?**
Age category (reference, <40)			
40–49 years old	1.72	0.95	1.53
50+ years old	0.84	0.68	1.37
Disease group (reference, CF)			
SCD	2.37	0.64	0.36
Diabetes	0.82	0.98	0.82
HIV	3.09*	1.29	1.72
BC, affected	1.16	1.14	1.32
BC, at risk	1.43	1.81	3.67[a]
CC, affected	2.00	0.96	1.64
CC, at risk	0.22	0.54	0.67
Income (reference, <$20K)			
$20–60K	2.40*	1.01	2.33[a]
>$60K	1.42	1.08	1.77
Marital status (reference, married/partnered)			
Divorced/separated	0.96	0.67	1.46
Widowed	0.71	0.87	3.05
Single	0.73	0.89	4.04[b]
Privacy level (reference, open)			
Neutral	1.50	1.28	2.85[b]
Private	1.05	0.88	2.32[a]

Here the odds quantities are the odds of answering yes to the question versus the odds of answering no. The odds ratios are odds in the indicator group/odds in the reference group. BC, breast cancer; CC, colon cancer.

[a] Significant at $P<0.05$.

[b] Significant at $P<0.001$.

TABLE VI

Percentage of Respondents who Would Still Care who got Medical Information About Them Everyone Could Get Good Health Coverage or if it Would not Affect Employment

Text of question	CF	SCD	Diabetes	HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
[a] I would not care who got medical information about me if everyone could get good health coverage									
Agree	58.6	53.1	55.5	39.1	58.0	26.7	76.1	48.0	52.0
Neutral	14.1	11.5	8.91	14.1	6.00	20.0	8.70	20.0	12.6
Disagree	27.3	35.4	35.6	46.7	36.0	53.3	15.2	32.0	35.4
I would not care who got medical information about me if knew it could not affect my job in any way									
Agree	41.8	42.7	41.4	35.2	50.0	18.2	48.9	38.0	40.0
Neutral	10.2	7.29	12.1	5.49	10.4	4.55	8.51	12.0	8.90
Disagree	48.0	50.0	46.5	59.3	39.6	77.3	42.6	50.0	51.1

BC, breast cancer; CC, colon cancer.

[a] Overall χ^2, $P<0.001$.

TABLE VII

Percentage of Respondents Reporting Job or Insurance Discrimination, by Medical Condition

Text of question	CF	SCD	Diabetes	HIV	BC affected	BC at risk	CC affected	CC at risk	Total
N (no.)	**102**	**99**	**104**	**100**	**50**	**45**	**47**	**50**	**597**
[a] 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
[a] Do you feel you were ever not hired or passed over for a job because of your condition?									
Yes	18.5	41.5	14.8	7.27	14.3	4.17	23.5	0.00	18.6
No	81.5	58.5	85.2	92.7	85.7	95.8	76.5	100	81.4
[a] Have you ever decided not to apply for a job because you were concerned they would ask about your condition?									
Yes	16.0	11.2	9.00	32.0	8.16	0.00	4.26	2.00	12.6
No	84.0	88.8	91.0	68.0	91.8	100	95.7	98.0	87.4

BC, breast cancer; CC, colon cancer.

[a] Overall χ^2, $P<0.001$.

TABLE VIII

Regression Models of Perceived Job and Insurance Discrimination

	Odds ratio		
Covariate	**Have you ever been denied health insurance/offered it at a prohibitive rate?**	**Do you feel you were ever not hired/passed over for a job because of your condition?**	**Have you ever decided not to apply for a job because you were concerned they would ask about your condition?**
Genetic disease (reference, non-genetic)			
Genetic	2.06[b]	3.71[b]	1.17
Age category (reference, <40)			
40–49 years old	1.21	C	3.51[b]
50+ years old	0.85	C	0.85
Income (reference, <$20K)			
$20–60K	1.26	0.82	0.55
>$60K	0.83	0.93	0.48
Marital status (reference, married/partnered)			
Divorced/separated	C	1.09	1.04
Widowed	C	C	5.94[a]
Single	C	2.34	3.92[b]
Race (reference, white)			
African-American	C	1.22	0.88
Other	C	1.91	0.82
Employment status (reference, full-time employed)			
Part-time employed	1.86[a]	1.10	1.33
Unemployed	1.40	1.33	1.00

Here the odds quantities are the odds of answering yes versus the odds of answering no. BC, breast cancer; CC, colon cancer.

[a] Significant at $P<0.05$.

[b] Significant at $P<0.01$.