

Patients' Perceptions About Medical Record Privacy and Security: Implications for Withholding of Information During the COVID-19 Pandemic



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INTRODUCTION

Some patients may withhold relevant medical information from their provider because of concerns about the security and privacy of their information, or about how their information will be used.¹ With increasing reliance on telemedicine and telehealth tools (e.g., patient portals) in response to the coronavirus disease 2019 (COVID-19) pandemic, this issue may be particularly problematic. As withholding information can compromise providers' ability to deliver appropriate care, the accuracy of public health surveillance system data, and even population health efforts to mitigate the spread of COVID-19, we need to understand how patients' concerns about the privacy and security of their medical information may lead to information-withholding behaviors.

METHODS

Data for the present study came from a survey administered to patients hospitalized at a large academic medical center (AMC) enrolled in a pragmatic randomized controlled trial (RCT).² The RCT studied the relationship between inpatient portal use and patients' care experience. One survey section asked about patients' attitudes toward use of health information technology, including their perceptions about information security risks and privacy. These questions were adapted from the National Cancer Institute's Health Information Technology National Trends Survey. The Institutional Review Board of the AMC approved this study.

The dependent variable for this study was the answer to the question "Have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record?" (yes/no). On the basis of previous research,³ we included four independent variables derived from answers to questions about medical information privacy and security:

1. "If your medical information is sent electronically from one health provider to another, how concerned are you that an unauthorized person will see it?"
2. "How confident are you that you have some say in who is allowed to collect, use, and share your medical information?"
3. "How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?"
4. "How interested are you in exchanging medical information electronically with a healthcare provider?"

A multivariable logistic regression model was used to test the relationship of the independent variables with information-withholding behavior, adjusting for patient demographics.

RESULTS

Table 1 summarizes patient characteristics and survey responses of our study participants. Results of our regression analysis (Table 2) show that for patients who were concerned that their medical information would be compromised if it was sent electronically between providers, the odds of withholding information from their provider was three times that of patients without concerns. Conversely, for patients who were confident about the privacy of their medical information, the odds of keeping information from their provider was approximately half of those who were not confident. Black patients were generally more likely to withhold information compared with White patients. Patients who were older, married, employed, and in good mental health and who had healthcare coverage were less likely to keep information from their provider.

DISCUSSION

Similar to previous research conducted in the general population,^{3, 4} our findings suggest that many hospitalized patients are concerned about who has access to their medical information, and we found an association between these concerns and patients' reported information-withholding behavior. While these findings were limited to the perceptions of patients from a single AMC, they are nonetheless important for providers to consider given relaxation of Health Insurance Portability and

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Table 1 Frequencies of Information-Withholding Behavior, Privacy and Security Concerns, and Patient Characteristics

Question	Answer	N = 3292
Dependent variable		
Kept information secret: have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record?	No	2438 (74.1)
	Yes	349 (10.6)
	Missing	505 (15.3)
Independent variable		
Unauthorized access: if your medical information is sent electronically from one health provider to another, how concerned are you that an unauthorized person will see it?	Not concerned	1091 (33.1)
	Concerned	1738 (52.8)
	Missing	463 (14.1)
Have say about medical information: how confident are you that you have some say in who is allowed to collect, use, and share your medical information?	Not confident	1414 (43.0)
	Confident	1519 (46.1)
	Missing	359 (10.9)
Safeguards in place: how confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?	Not confident	1674 (50.9)
	Confident	1129 (34.3)
	Missing	489 (14.9)
Exchanging information electronically: how interested are you in exchanging medical information electronically with a healthcare provider?	Not interested	938 (28.5)
	Interested	1935 (58.8)
	Missing	419 (12.7)
Patient characteristic		
Race [†]	White	2574 (78.2)
	Black	593 (18.0)
	Other	125 (3.8)
Gender [†]	Female	1972 (59.9)
	Male	1320 (40.1)
Age [†]	Mean (SD)	46.8 (15.0)
	Marital status: what is your marital status?	Not married
Education: what is the highest grade or level of school that you have completed?	Married	1251 (38.0)
	Missing	651 (19.8)
	Less than high school	154 (4.7)
	High school	724 (22.0)
	Some college	828 (25.2)
	College graduate	712 (21.6)
	Graduate or beyond	326 (9.9)
Household income: in the last 12 months, what is your total household income, including income from all sources (wages, salaries, investment income, Social Security, retirement benefits, or help from a relative)?	Missing	548 (16.6)
	\$0–\$19,999	893 (27.1)
	\$20,000–\$34,999	387 (11.8)
	\$35,000–\$49,999	272 (8.3)
	\$50,000–\$74,999	364 (11.1)
	\$75,000–\$99,999	232 (7.0)
	\$100,000 or more	373 (11.3)
	Missing	771 (23.4)
	Unemployed	1160 (35.2)
	Employed	1146 (34.8)
Employment: which of the following best describes your employment status last week?	Retired	341 (10.4)
	Missing	645 (19.6)
	No	213 (6.5)
	Yes	2387 (72.5)
Healthcare coverage: do you have any kind of healthcare coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid/Medicare?	Missing	692 (21.0)
	Do not agree	1638 (49.8)
	Agree	1320 (40.1)
Self-care: I am confident that I know how to take care of my health...	Missing	334 (10.1)
	Not good	1315 (39.9)
	Good	1375 (41.8)
General health: would you say your health is...	Missing	602 (18.3)
	Not good	1408 (42.8)
	Good	1262 (38.3)
Mental health: how would you rate your mental health, including your mood and your ability to think?	Missing	622 (18.9)

*Unless noted otherwise

[†]Data derived from the academic medical center's information warehouse

Accountability Act (HIPAA) protections in response to COVID-19. Specifically, the U.S. Office for Civil Rights has granted business associates (e.g., healthcare clearinghouses) the ability to make good-faith disclosures of personal medical information for public health activities as long as the patient is informed within 10 days.⁵

In order to protect against potential adverse impacts of this rule on disclosure, providers likely need to reinforce

technological safeguards, such as secure and encrypted communication, and clearly communicate about how patients' medical information is accessed, stored, and used in order to honor patient privacy preferences⁶ and potentially address patients' concerns in this area. Monitoring the impact of these changes on patients' information-withholding behavior will be critical to ensure providers have the appropriate information to enable delivery of high-quality care.

Table 2 Multivariable Logistic Regression Model for Patient Information-Withholding Behavior

Independent variable*	Have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record?		Adjusted OR (95% CI)
	No n (%)	Yes n (%)	
Unauthorized access			
Not concerned	1026 (42.1)	55 (15.9)	–
Concerned	1410 (57.9)	291 (84.1)	3.26 (2.26–4.78)
Have say about medical information			
Not confident	1116 (46.0)	210 (61.0)	–
Confident	1312 (54.0)	134 (39.0)	0.48 (0.33–0.69)
Safeguards in place			
Not confident	1424 (58.6)	236 (67.8)	–
Confident	1008 (41.4)	112 (32.2)	1.26 (0.86–1.84)
Exchanging information electronically			
Not interested	791 (32.5)	125 (35.9)	–
Interested	1644 (67.5)	223 (64.1)	1.19 (0.87–1.63)
Race			
White	1974 (81.0)	246 (70.5)	–
Black	379 (15.5)	85 (24.4)	1.55 (1.07–2.20)
Other	85 (3.5)	18 (5.2)	1.27 (0.60–2.48)
Gender			
Female	1461 (59.9)	201 (57.6)	–
Male	977 (40.1)	148 (42.4)	1.20 (0.89–1.61)
Age			
Mean (SD)	47.0 (15.1)	44.4 (12.6)	0.99 (0.98–1.00)
Marital status			
Not married	1105 (50.1)	211 (69.6)	–
Married	1100 (49.9)	92 (30.4)	0.59 (0.41–0.84)
Education			
Less than high school	115 (5.0)	34 (10.8)	–
High school	598 (26.1)	86 (27.4)	0.75 (0.44–1.31)
Some college	694 (30.3)	100 (31.8)	0.68 (0.40–1.19)
College graduate	605 (26.4)	66 (21.0)	0.69 (0.38–1.27)
Graduate or beyond	278 (12.1)	28 (8.9)	0.70 (0.34–1.45)
Household income			
\$0–\$19,999	708 (33.3)	151 (53.0)	–
\$20,000–\$34,999	342 (16.1)	31 (10.9)	0.53 (0.32–0.87)
\$35,000–\$49,999	240 (11.3)	15 (5.3)	0.48 (0.24–0.90)
\$50,000–\$74,999	313 (14.7)	39 (13.7)	1.13 (0.68–1.84)
\$75,000–\$99,999	205 (9.6)	16 (5.6)	0.70 (0.34–1.34)
\$100,000 or more	321 (15.1)	33 (11.6)	1.34 (0.74–2.39)
Employment			
Unemployed	927 (41.8)	174 (59.0)	–
Employed	996 (44.9)	98 (33.2)	0.68 (0.47–0.97)
Retired	294 (13.3)	23 (7.8)	0.85 (0.45–1.55)
Healthcare coverage			
No	171 (7.7)	34 (11.6)	–
Yes	2043 (92.3)	258 (88.4)	0.57 (0.37–0.92)
Self-care			
Do not agree	1265 (53.9)	212 (63.5)	–
Agree	1084 (46.1)	122 (36.5)	0.80 (0.58–1.08)
General health			
Not good	1083 (47.8)	166 (53.4)	–
Good	1182 (52.2)	145 (46.6)	1.19 (0.86–1.65)
Mental health			
Not good	1148 (50.9)	205 (66.6)	–
Good	1107 (49.1)	103 (33.4)	0.66 (0.47–0.91)

*Definitions for each variable can be found in Table 1

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