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. 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). 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, 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, 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
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 preferences\(^6\) 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.

| 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 1915 (58.8)                                               |          |
|                                                                         | Missing 419 (12.7)                                                   |          |
| Patient characteristic                                                   |                                                                        |          |
| Race\(^†\)                                                              | White 2574 (78.2)                                                    |          |
|                                                                         | Black 591 (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 1390 (42.2)                                              |          |
|                                                                         | Married 1251 (38.0)                                                  |          |
|                                                                         | Missing 651 (19.8)                                                   |          |
| Education: what is the highest grade or level of school that you have completed? | 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)                                        |          |
|                                                                         | Missing 548 (16.6)                                                   |          |
| 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)? | $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)                                         |          |
| Employment: which of the following best describes your employment status last week? | Missing 771 (23.4) |          |
|                                                                         | Unemployed 1160 (35.2)                                              |          |
|                                                                         | Employed 1146 (34.8)                                                |          |
|                                                                         | Retired 341 (10.4)                                                   |          |
|                                                                         | Missing 645 (19.6)                                                   |          |
| 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? | No 213 (6.5) |          |
|                                                                         | Yes 2387 (72.5)                                                     |          |
| Self-care: I am confident that I know how to take care of my health…    | Do not agree 1638 (49.8)                                            |          |
|                                                                         | Agree 1320 (40.1)                                                   |          |
|                                                                         | Missing 334 (10.1)                                                   |          |
| General health: would you say your health is…                           | Not good 1315 (39.9)                                                |          |
|                                                                         | Good 1375 (41.8)                                                    |          |
|                                                                         | Missing 602 (18.3)                                                   |          |
| Mental health: how would you rate your mental health, including your mood and your ability to think? | Not good 1408 (42.8) |          |
|                                                                         | Good 1262 (38.3)                                                    |          |
|                                                                         | Missing 622 (18.9)                                                   |          |

*Unless noted otherwise
\(^†\)Data derived from the academic medical center’s information warehouse
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Table 2 Multivariable Logistic Regression Model for Patient Information-Withholding Behavior

| Independent variable* | No (%) | Yes (%) | Adjusted OR (95% CI) |
|-----------------------|--------|---------|---------------------|
| Have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record? |        |         |                     |
| Unauthorized access   | 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   | 1424 (58.6) | 236 (67.8) |                     |
| Not confident         | 1008 (41.4) | 112 (32.2) | 1.26 (0.86–1.84) |
| Confident             |         |         |                     |
| 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) |                     |
| 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              | 966 (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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Compliance with Ethical Standards:

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