INTRODUCTION
Over 40 million Americans provide unpaid support to an adult relative for tasks including accompanying them to doctor visits and/or supporting them in medical decisions. Over the past several years—and particularly amid COVID-19—there has been increasing interest and demand for caregivers to be more involved in communication with providers to support patient engagement and patient-centered care as evidenced by recent state and federal policy initiatives to expand support to caregivers. One way to improve communication between caregivers and providers is through an online medical record (patient portal), which enables patients to acquire important health information and communicate with medical providers. However, caregivers’ access to adult care recipients’ portals is limited and varies across healthcare organizations and states. The objective of this study was to determine the relationship between socio-demographic attributes and responsibilities of caregivers and likelihood of (a) communicating with recipients’ providers and (b) accessing recipients’ online records.

METHODS
We performed a secondary analysis of data from the National Cancer Institute’s nationally representative 2018 Health Information National Trends Survey (HINTS) 5 Cycle 2, administered to 3504 US adults between January and May 2018. Our final analytic sample included 191 self-identified family caregivers of adults supporting the following: (a) a spouse/partner (n = 51), (b) a parent/parents (n = 101), or (c) another family member (n = 39).

RESULTS
The majority of family caregivers of adults (74–89%) report responsibility for communicating with care recipients’ healthcare providers (Table 1). However, only 11–27% of caregivers accessed their care recipients’ online medical record in the previous 12 months, with caregivers of spouses most likely to access care recipient’s online record. In multivariable analysis (Table 2), caregivers of a parent were significantly less likely than caregivers of spouses to report being responsible for communicating with providers (OR = 4.34, p = 0.003). Similarly, caregivers supporting a parent were significantly less likely than those supporting a spouse/partner to report using the online medical record (OR = 0.28, p = 0.01).

DISCUSSION
Most family caregivers are responsible for communicating with healthcare providers for their adult care recipients. Few family caregivers, however, are accessing the online medical records of their care recipients. Family caregivers of parents and other adult family relatives are less likely than caregivers of a spouse/partner to access their recipient’s online medical records. Access to information about care recipient’s diagnoses, test results, and prognosis can enable caregivers to give providers helpful contextualizing details about care recipients’ symptoms or behaviors, to advocate for their relative’s needs and preferences, and to provide effective support. Public health disasters like the COVID-19
pandemic demonstrate the need for patients to access care providers without requiring in-person visits. The rapid expansion of innovations like telehealth, including access to patient portals, during the pandemic demonstrates that it is possible to increase use of these technologies. COVID-19 also reveals challenges, including disparities in access to these resources.\(^5\) We find that prior to the pandemic few family caregivers of adults were using online portals despite being responsible for communication. This is concerning and suggests a need for policies and practices to encourage and enable greater access by family caregivers. Providers should identify whether their patients have a family caregiver who should be involved in care discussions and could benefit from accessing the online medical record. They should discuss with patients and caregivers any concerns (e.g., about privacy and confidentiality) or preferences regarding access to the online medical record, as well as implications of caregiver record access.\(^3\) For instance, caregivers who are adult children may see inheritable risk factors when viewing the online record or may learn about a parent’s medical history (e.g., stigmatized conditions) that the parent may want kept private. Alternatively, patients may want their caregiver to be aware of important decisions such as do not resuscitate preferences. As such, robust proxy access procedures as

| Table 1 Types and characteristics of caregivers and caregiving (n = 191) |
|---------------------------------------------------------------|
| Demographic characteristics                                   |
| Age               | Spouse n = 51 | Parent n = 101 | Another family member n = 39 | Test statistic and p value |
| Gender            |              |               |                            | ANOVA                      |
| Female            | 58.82        | 67.33         | 71.79                      | 1.82 (p = 0.40)             |
| Male              | 41.18        | 32.67         | 28.21                      |                             |
| Education         |              |               |                            | Chi-squared                |
| Less than high school | 1.96       | 0.00          | 2.56                       | 4.45 (p = 0.616)            |
| High school equivalent | 15.69      | 8.91          | 10.26                      |                             |
| Some college      | 33.33        | 34.65         | 38.46                      |                             |
| BA or higher      | 49.02        | 56.44         | 48.72                      |                             |
| Race/ethnicity    |              |               |                            | Chi-squared                |
| White, non-Hispanic | 70.59      | 65.35         | 64.10                      | 0.54 (p = 0.762)            |
| Not White and/or Hispanic | 29.41 | 34.65 | 35.90 |                             |
| Employment        |              |               |                            | Chi-squared                |
| Employed          | 35.29        | 53.47         | 48.72                      | 4.51 (p = 0.105)            |
| Not employed      | 64.71        | 46.53         | 51.28                      |                             |
| Location and duration of caregiving                           |
| Duration of caregiving |              |               |                            | ANOVA                      |
| Less than or equal to 5 years | 60.78    | 73.27         | 56.41                      | 4.61 (p = 0.100)            |
| More than 5 years   | 39.22        | 26.73         | 43.59                      |                             |
| Proximity to care recipient                                  |
| Lives in the same household | 92.16   | 24.75         | 43.59                      | 62.35 (p < 0.001)           |
| Within 1 h         | 7.84         | 56.44         | 41.03                      | Fisher’s exact test         |
| More than 1 h      | 0            | 18.81         | 15.38                      |                             |
| Hours per week (mean [s.d.])                                 |
| 46.06 (51.14)      | 20.59        | 24.21 (35.57) | 7.03 (p = 0.001)           |                             |
| Health conditions of care recipients                         |
| Supports physical condition                                  |
| 100.00            | 100.00       | 100.00        | No difference              | Pearson’s Chi-squared       |
| Supports physical and cognitive condition                     |
| 41.18             | 57.43        | 61.54         | 4.74 (p = 0.093)           | Pearson’s Chi-squared       |
| Types of support provided                                    |
| Provides activity of daily living assistance\(^a\) | 56.86        | 41.58         | 33.33                      | 5.47 (p = 0.065)            |
| Provides instrumental activity of daily living assistance\(^b\) |
| 100.00            | 99.01        | 100.00        | 0.90 (p = 0.639)           | Pearson’s Chi-squared Fisher’s exact test |
| Responsibilities for communication with healthcare providers  |
| Responsible for communicating with care recipient’s healthcare providers | 68.63 | 89.11 | 74.36 | 10.33 (p = 0.006) |
| Accessed care recipient’s online medical record in the past 12 months | 27.45 | 11.88 | 12.82 | 6.46 (p = 0.04) |

\(^a\)Activities of daily living include feeding, dressing, bathing, toileting, and movement in and out of bed

\(^b\)Instrumental activities of daily living include shopping, transportation, and preparing meals
well as discussions about privacy and confidentiality regarding online medical record access are critical among adult care recipients and their caregivers.1,6

| Type of family care recipient | Responsible for communicating | Accessed online medical record |
|------------------------------|-------------------------------|-------------------------------|
| Spouse                       | Ref                           | Ref                           |
| Parent                       | 4.34                          | 0.093                         |
| Another family member        | 1.23                          | 0.701                         |
| Gender                       |                               |                               |
| Male                         | Ref                           | Ref                           |
| Female                       | 2.01                          | 0.098                         |
| Race/ethnicity               |                               |                               |
| Hispanic and/or non-White    | Ref                           | Ref                           |
| White non-Hispanic           | 2.37                          | 0.033                         |
| Education                    |                               |                               |
| High school or less          | Ref                           | Ref                           |
| Some college                 | 1.57                          | 0.481                         |
| BA or higher                 | 2.11                          | 0.231                         |
| Provides ADL assistance      |                               |                               |
| No                           | Ref                           | Ref                           |
| Yes                          | 0.82                          | 0.647                         |
| Supports cognitive condition |                               |                               |
| No                           | Ref                           | Ref                           |
| Yes                          | 2.46                          | 0.034                         |
| Hours spent caregiving per week | 1.01                         | 0.057                         |

Italicized values represent p < 0.05

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