

# Family Caregiver Access of Online Medical Records: Findings from the Health Information National Trends Survey



J Gen Intern Med 36(10):3267–9  
DOI: 10.1007/s11606-020-06350-8  
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## 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.<sup>1</sup> 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.<sup>2,3</sup> 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.<sup>4</sup> However, caregivers' access to adult care recipients' portals is limited and varies across healthcare organizations and states.<sup>2</sup> 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 ( $n = 39$ ).

Received June 30, 2020

Revised August 11, 2020

Accepted November 16, 2020

Published online December 2, 2020

We first examined socio-demographic attributes and responsibilities of caregivers. We estimated multivariable logistic regression models to investigate relationships between care recipient type and (1) responsibility for communicating with providers and (2) accessing care recipient's online medical records. Models adjusted for age, race/ethnicity, sex, education, activities of daily living support, cognitive condition support, proximity to care recipient, and hours spent caregiving.

## 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.<sup>5</sup> Public health disasters like the COVID-19

Table 1 Types and characteristics of caregivers and caregiving (n = 191)

	Spouse n = 51 %	Parent n = 101 %	Another family member n = 39 %	Test statistic and p value	Test performed
Demographic characteristics					
Age	66.33	56.04	55.87 (14.93)	11.76 (p < 0.001)	ANOVA
Mean (s.d.)	(14.19)	(11.59)			
Gender				1.82 (p = 0.40)	Pearson's Chi-squared
Female	58.82	67.33	71.79		
Male	41.18	32.67	28.21		
Education				4.45 (p = 0.616)	Pearson's Chi-squared
Less than high school	1.96	0.00	2.56		
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				0.54 (p = 0.762)	Pearson's Chi-squared
White, non-Hispanic	70.59	65.35	64.10		
Not White and/or Hispanic	29.41	34.65	35.90		
Employment				4.51 (p = 0.105)	Pearson's Chi-squared
Employed	35.29	53.47	48.72		
Not employed	64.71	46.53	51.28		
Location and duration of caregiving					
Duration of caregiving				4.61 (p = 0.100)	
Less than or equal to 5 years	60.78	73.27	56.41		
More than 5 years	39.22	26.73	43.59		
Proximity to care recipient				62.35 (p < 0.001)	Fisher's exact test
Lives in the same household	92.16	24.75	43.59		
Within 1 h	7.84	56.44	41.03		
More than 1 h	0	18.81	15.38		
Hours per week (mean [s.d.])	46.06 (51.14)	20.59 (35.36)	24.21 (35.57)	7.03 (p = 0.001)	ANOVA
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 <sup>a</sup>	56.86	41.58	33.33	5.47 (p = 0.065)	Pearson's Chi-squared
Provides instrumental activity of daily living assistance <sup>b</sup>	100.00	99.01	100.00	0.90 (p = 0.639)	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)	Pearson's Chi-squared
Accessed care recipient's online medical record in the past 12 months	27.45	11.88	12.82	6.46 (p = 0.04)	Pearson's Chi-squared

<sup>a</sup>Activities of daily living include feeding, dressing, bathing, toileting, and movement in and out of bed

<sup>b</sup>Instrumental activities of daily living include shopping, transportation, and preparing meals

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.<sup>5</sup> 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.<sup>3</sup> 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 2 Odds ratios of family caregiver characteristics to responsibility for communicating with providers and having accessed the online medical record, adjusting for demographic factors, and caregiving responsibilities**

	Responsible for communicating Odds ratio (OR)	<i>p</i> Value	Accessed online medical record Odds ratio (OR)	<i>p</i> Value
Type of family care recipient				
Spouse	Ref	Ref	Ref	Ref
Parent	4.34	<i>0.003</i>	0.28	<i>0.011</i>
Another family member	1.23	0.701	0.32	0.067
Gender				
Male	Ref	Ref	Ref	Ref
Female	2.01	0.098	1.82	0.200
Race/ethnicity				
Hispanic and/or non-White	Ref	Ref	Ref	Ref
White non-Hispanic	2.37	<i>0.033</i>	0.55	0.171
Education				
High school or less	Ref	Ref	Ref	Ref
Some college	1.57	0.481	1.77	0.441
BA or higher	2.11	0.231	1.74	0.443
Provides ADL assistance				
No	Ref	Ref	Ref	Ref
Yes	0.82	0.647	1.30	0.566
Supports cognitive condition				
No	Ref	Ref	Ref	Ref
Yes	2.46	<i>0.034</i>	1.77	0.196
Hours spent caregiving per week	1.01	0.057	1.0	0.591
Responsible for communicating with care recipient's healthcare providers	-	-	1.12	0.832

*Italicized values represent  $p < 0.05$*

well as discussions about privacy and confidentiality regarding online medical record access are critical among adult care recipients and their caregivers.<sup>3,6</sup>

Bradley Iott, MPH, MS<sup>1,2</sup>  
Minakshi Raj, PhD<sup>3</sup>  
Jodyn Platt, PhD<sup>4</sup>  
Denise Anthony, PhD<sup>1</sup>

<sup>1</sup>Department of Health Management and Policy,  
University of Michigan School of Public Health,  
Ann Arbor, MI, USA

<sup>2</sup>School of Information, University of Michigan,  
Ann Arbor, MI, USA

<sup>3</sup>Department of Kinesiology and Community Health,  
University of Illinois-Urbana Champaign,  
Champaign, IL, USA

<sup>4</sup>Department of Learning Health Sciences, University  
of Michigan Medical School,  
Ann Arbor, MI, USA

**Corresponding Author:** Bradley Iott, MPH, MS; School of Information, University of Michigan, Ann Arbor, MI, USA (e-mail: biott@umich.edu).

#### Compliance with Ethical Standards:

**Conflicts of Interest:** The authors declare that they have no conflict of interest.

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