Caregivers' Use of Patient Portals: Findings from a 2019 National Survey

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INTRODUCTION

Patient portals provide access to health information, creating the conditions necessary for patient engagement.¹ However, digital disparities limit engagement with portals.¹ To reduce these disparities, some healthcare systems have expanded portal access to informal caregivers, like spouses, or family members. Patients—particularly those with low digital literacy or complex health needs—have expressed interest in sharing portal access with caregivers^{2,3}; however, few healthcare systems enable patients to share portal access.^{4,5} Instead, some patients informally share log-on information with caregivers, creating challenges for healthcare systems in recognizing whether portal activity is from patients or caregivers.⁴ To date, there have been no nationally representative studies that estimate how often caregivers access portals or which caregivers are most likely to have access. Our study has two objectives¹: estimate the prevalence of portal usage among caregivers in a nationally representative sample and² examine predictors of portal usage.

METHODS

Data were obtained from the 2019 Health Information National Trend Survey (HINTS) ($n = 4200$ adults and 612 informal caregivers). HINTS measures portal usage for self-care and as part of caregiving activities in the past 12 months using separate questions. We included variables associated with portal usage including demographics and presence of a chronic or mental health condition.¹ For caregivers, we also included relation to patient (e.g., child), and health condition of the patient.

We compared portal usage for self-care and for caregiving based on sample characteristics. We conducted two multivariable logistic regressions to examine which characteristics were associated with portal usage for self-care and caregiving. Statistical analyses were conducted in Stata (version 16). We applied sampling and jackknife replicate weights to develop

nationally representative estimates and account for complex survey design. This study was exempted by the Advarra Institutional Review Board.

RESULTS

The sample contained 4200 adults; 612 identified as informal caregivers (Table 1). Less than half of adults (42.5%) used portals for self-care and less than a third of caregivers (31.4%) used portals for caregiving. In multivariable analyses, individuals under 65 were more likely to use a portal for self-care (OR: 1.22, $P = 0.009$) and caregiving (OR: 1.77, $P = 0.03$) (Table 2). Having an income $> \$75,000$ annually was associated with higher odds of portal use for self-care (OR: 3.39, $P < 0.001$) and caregiving (OR: 3.02, $P = 0.003$) compared to having an income of $< \$20,000$ annually. Having a chronic health condition was associated with greater odds of portal use for self-care (OR: 1.33, $P < 0.001$) but not for caregiving. Having a mental health condition was associated with greater odds of portal use for self-care (OR: 1.23, $P = 0.01$) but reduced odds of portal use for caregiving (OR: 0.61, $P = 0.03$). Caring for a patient with a chronic condition was associated with greater odds of portal use for caregiving (OR: 1.66, $P = 0.022$). Caring for a patient with a mental health condition was associated with greater odds of portal use for caregiving (OR: 1.71, $P = 0.013$).

DISCUSSION

In the USA, 53 million adults serve as caregivers and help patients with tasks that could be completed through the patient portal (e.g., scheduling appointments, communicating with providers).⁶ Our study found that a third of caregivers use portals nationally, demonstrating interest in shared portal access. Prior studies suggest that granting caregiver access to portals can be cumbersome (e.g., lengthy credentialing process) and may not meet patients' needs (e.g., inability to align information sharing with patient preferences).^{4,7} Our study found that digital disparities hindered caregivers' access to patient portals; older caregivers and caregivers with fewer economic resources were less likely to use the portal. Race and ethnicity were not associated with caregiver portal use; however, further studies are needed to examine this relationship. Healthcare systems may need to develop iPad loan programs and digital literacy training that target both patients

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Table 1 Sample Characteristics

Characteristics	Patients' portal use		P	Caregivers' portal use		P
	All <i>n</i> = 4200 <i>W</i> = 199696652	Users <i>n</i> = 1785 <i>W</i> = 81927907		All <i>n</i> = 612 <i>W</i> = 29980581	Users <i>n</i> = 192 <i>W</i> = 10148918	
Age, mean (SD)	55.8 (16.6)	54.1 (16.0)	< 0.001	54.7 (14.3)	52.0 (14.2)	< 0.001
Under 65, <i>N</i> (%)	2772 (66.0)	1249 (70.0)		461 (75.3)	155 (80.7)	
Male gender, <i>N</i> (%)	1818 (43.3)	703 (38.7)	< 0.001	223 (36.4)	62 (32.3)	0.07
Black race, <i>N</i> (%)	706 (16.8)	238 (33.7)	< 0.001	112 (18.3)	30 (15.6)	0.20
Hispanic ethnicity, <i>N</i> (%)	617 (14.7)	220 (35.7)	< 0.001	89 (14.5)	33 (17.2)	0.57
Education, <i>N</i> (%)						
High school diploma or less	877 (20.9)	674 (31.7)	< 0.001	270 (44.1)	68 (35.4)	0.002
College degree	1195 (28.5)	597 (49.9)		184 (30.1)	65 (33.9)	
Postgraduate	2128 (50.7)	514 (58.6)		158 (25.8)	59 (30.7)	
Income, <i>N</i> (%)						
Less than \$20,000	718 (17.1)	149 (20.8)	< 0.001	83 (13.6)	14 (7.3)	0.005
\$20,000 to \$34,999	521 (12.4)	161 (30.9)		69 (11.3)	18 (9.4)	
\$35,000 to \$49,999	538 (12.8)	222 (41.3)		76 (12.4)	24 (12.5)	
\$50,000 to \$74,999	755 (18.0)	353 (46.8)		115 (18.8)	37 (19.3)	
\$75,000 or more	1668 (39.7)	900 (53.9)		269 (44.0)	99 (51.6)	
Rural residence, <i>N</i> (%)	449 (10.7)	152 (33.9)	< 0.001	63 (10.3)	16 (8.3)	0.18
Chronic condition, <i>N</i> (%)	2284 (54.4)	955 (41.8)	0.33	212 (34.6)	82 (42.7)	0.02
Mental health condition, <i>N</i> (%)	939 (22.4)	423 (45.1)	0.07	158 (25.8)	65 (33.9)	0.003
Caregiver chronic condition, <i>N</i> (%)	n/a	n/a	n/a	329 (53.8)	99 (51.6)	0.16
Caregiver mental condition, <i>N</i> (%)	n/a	n/a	n/a	171 (27.9)	43 (22.4)	0.06
Relation to patient, <i>N</i> (%)						
Child	n/a	n/a	n/a	155 (25.4)	53 (27.6)	0.001
Spouse/partner	n/a	n/a	n/a	144 (23.5)	54 (28.1)	
Parent	n/a	n/a	n/a	206 (33.7)	61 (31.8)	
Friend or other family member	n/a	n/a	n/a	107 (17.4)	24 (12.5)	

and caregivers to overcome digital disparities. Furthermore, implementation research is needed to determine best practices for caregiver proxy access (e.g., which patient information to share, what resources caregivers value). This study has several limitations. Data are self-report which may be prone to bias

and were only available for 2019 so we cannot examine trends in portal use. Overall, our study found that many informal caregivers use patient portals for caregiving activities. Further research is needed to understand how healthcare systems can optimize the use of portals for caregiver and patient needs.

Table 2 Predictors of Portal Use

	Patients' portal use			Caregivers' portal use		
	<i>n</i> = 4200			<i>n</i> = 612		
	<i>W</i> = 199696652			<i>W</i> = 29980581		
	OR	95% CI	P value	OR	95% CI	P value
Under 65	1.22	1.05–1.42	0.009	1.77	1.07–2.94	0.03
Male gender	0.67	0.59–0.77	0.04	0.66	0.45–0.98	0.04
Black race	0.77	0.64–0.93	0.006	0.75	0.46–1.24	0.26
Hispanic ethnicity	0.80	0.66–0.96	0.017	1.39	0.83–2.34	0.21
Education						
High school diploma or less (ref)						
College degree	1.63	1.29–2.06	< 0.001	1.51	0.97–2.36	0.07
Postgraduate	2.23	1.72–2.89	< 0.001	1.48	0.91–2.42	0.12
Income						
Less than \$20,000 (ref)						
\$20,000 to \$34,999	1.62	1.24–2.11	0.07	1.83	0.80–4.23	0.15
\$35,000 to \$49,999	2.45	1.89–3.17	0.002	2.13	0.96–4.73	0.06
\$50,000 to \$74,999	2.89	2.28–3.69	0.002	2.28	1.08–4.82	0.03
\$75,000 or more	3.39	2.70–4.27	< 0.001	3.02	1.47–6.22	0.003
Rural residence	0.70	0.49–1.00	0.003	0.83	0.43–1.60	0.59
Chronic condition	1.33	1.15–1.53	< 0.001	2.01	1.32–3.07	0.001
Mental health condition	1.23	1.05–1.44	0.01	1.99	1.31–3.03	0.001
Caregiver chronic condition	n/a	n/a	n/a	1.08	0.74–1.58	0.70
Caregiver mental condition	n/a	n/a	n/a	0.61	0.39–0.96	0.03
Relation to patient						
Child	n/a	n/a	n/a	1.31	0.75–2.29	0.35
Spouse/partner	n/a	n/a	n/a	1.79	1.05–3.06	0.03
Parent	n/a	n/a	n/a	0.68	0.39–1.19	0.18
Friend/family member	n/a	n/a	n/a	0.62	0.33–1.15	0.13

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Compliance with Ethical Standards:

Conflict of Interest: Dr. Otto reports grants from National Cancer
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