9-15-2019

Digital Divide Among Caregivers of Chronic Disease Patients

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Expansive and rapid growth of technology creates unprecedented patient access to health information, including timely communication with care providers via patient portals and the ability to access information regarding specific disease(s) (e.g., cancer). However, several forms of digital engagement with health providers require access and use of reliable internet access. A "digital divide" is used to describe demographic differences which contribute to a patient's use or disuse of patient portals; prior research have noted disparities in lack of reliable internet access. Despite the prevalence of informal caregivers in patient care, little is known about internet access and use among informal caregivers of patients with chronic disease. This study leveraged the 2017 Behavioral Risk Factor Surveillance System (BRFSS) dataset to determine population level characteristics of caregiver factors which may contribute to their internet access and use. Findings illuminate informal caregivers primarily care for patients with illnesses relating to aging, including dementia. We also found that non-use of the internet (NUI) was higher among caregiver groups who informally provided care between 20-39 hours/week as opposed to those with 0-8 hours of provided care each week. Unlike caregivers of asthma, cancer and dementia; caregivers of substance use, diabetes, HIV and chronic respiratory disease patients reported higher NUI. Future studies should target the specific needs of informal caregivers such that tools promoting patient engagement and access to resources do not unintentionally neglect this user group.

INTRODUCTION

Internet-enabled modes of communication such as patient portals are increasingly becoming an effective tool for health care delivery (Tieu et al., 2015). The internet serves as the basis for health information technology (IT) for consumers, such as personal health records, secure electronic messaging, and transmission of medical data from home-based devices, which can improve both patient-provider communication and patient- centered care (Ralston et al., 2009).

Unfortunately, the internet is not readily accessible to all patient groups, with less educated, economically disadvantaged, and socially marginalized persons being least likely to access health information through the internet (Kalichman et al., 2002). This disparity in reliable internet access may widen among caregivers in disadvantaged population(s); namely, there are peculiar caregiver characteristics (such as caregiver burden) that may influence internet access and use.

Internet use among informal caregivers

Non-professional caregivers, also known as in- formal caregivers (who are usually family members), are instrumental in caring for chronic disease patients. It is estimated that informal caregiving will be the largest source of long-term care services in the US, increasing 85% from 2000 to 2050 (Hu, Kung, Rummans, Clark, & Lapid, 2014). Internet use among some types of caregivers has been recorded. For example, in a recent study, 94% of cancer caregivers reported to having used the internet (Lapid et al., 2015). Another study on caregivers of dementia showed that about 97% of caregivers have used the internet in the past (Kajiyama et al., 2013).

Caregivers benefit from internet access and use. Internet access and use can alleviate care burden by connecting caregivers to support groups as well as giving them more direct access to communicate with health care professionals (Lapid et al., 2015). While these key benefits associated with caregiver internet use should alleviate caregiver burden, little is known on characteristics of caregivers who leverage the internet as an information and communication tool. This need deepens considering the potential additional caregiver burdens including intensity of the care needed, including

the health conditions of the patients for whom caregivers provide support. This leaves a need to explore and compare internet use by caregivers across the health conditions of care recipients, and caregiver burden.

The purpose of this exploratory study was to examine (a) the non-use of the internet (NUI) among caregivers by patient's health problem. (b) The association between NUI and objective caregiver burden (OCB).

METHODS

To answer our two main research questions, we leveraged a publicly available dataset, weighing the sample according to weights provided by dataset manual. This in turn allows us to make inferences regarding population level trends and differences in caregiver internet use.

Sample

Data from the 2017 Behavioral Risk Factor Surveillance System (BRFSS) was used for this study. The BRFSS is a representative telephone-based survey of health behaviors and health risks that is conducted by the Centers for Disease Control and Prevention (CDC) in partnership with health departments in all 50 US states, the District of Columbia, and US territories (CDC, 2017). In 2017, the 'internet' question was administered to all the states. However, the caregiving module was implemented by 12 states (Alaska, Hawaii, New Mexico, Oregon, Rhode Island, Kansas, Michigan, New Jersey, New York, Oklahoma, Utah, Maryland). We restricted our analysis to individuals who received both the care- giver and the internet modules, yielding an analytical sample of 4,911 respondents.

Measures

Outcome variable. The non-use of the internet was assessed using the question: Have you used the internet in the past 30 days? Response options were 'Yes' and 'No'.

Exposure variable. Objective burden by asking caregivers to estimate the total hours per week they spent providing care to the care recipient. Responses were

categorized as 0-8h, 9-19h, 20-39h and ≥ 40h (Hughes et al., 2014). Caregivers were also asked, how long they have provided care for the care recipient?" Responses ranged from "≤6mo to ≥5years".

Covariates. Demographic variables included age, sex, race, income, employment status, education level, and major health problem of the care recipient.

Statistical Analysis

Bivariate and multivariate logistic regression were used to examine the association between NUI, caregiver burden and other caregiver characteristics. Model 1 adjusted for sociodemographic characteristics while Model 2 included socioeconomic status. SAS 9.4 software (SAS Institute, Cary, NC) was used for all statistical analyses.

RESULTS

Sample characteristics. Descriptive characteristics of the caregiver sample (N=4,911) and weighted percentages are presented in Table 1.

Table 1. Characteristics of caregivers (N= 4918)

Variable[1]	Frequency (N)	Weighted %	% NUI (N=720)	P-value	Variable[1]	N	Weighted %	% NUI (N=720)	P-value
					Self employed	489	9.80	7.55	
					Unemployed	2447	49.02	22.05	
Sex				0.0073	**Hours spent providing care weekly**				<0.0001
Female	3062	61.57	11.98						
Male	1852	38.43	15.63		0-8 h	2725	59.50	10.25	
Income				<0.0001	9-19 h	613	12.74	10.22	
< $15,000	427	9.16	27.86		20- 39h	501	10.53	16.00	
$15,000 t0 <$25000	729	17.33	25.19		≥40+	815	17.23	23.02	
$25,000 t0 <$35000	461	11.21	17.09		**Caregiving length**				0.05
$35,000 t0 <$50000	590	12.83	13.12		0-6mo	1484	30.08	10.62	
$50,000+	2141	49.46	3.33		6mo-2y	895	19.85	13.53	
Education				<0.0001	2 year-<5 years	962	20.01	13.53	
No High school	253	5.81	45.28		>5 yrs	1487	30.06	15.26	
Graduate High School	1151	22.70	22.71		**Health condition of care recipient**				0.026
Attend college	1537	31.87	12.06						
Grad college	1969	39.61	4.27		Arthritis	223	4.46	14.35	
Age				<0.0001	HIV	6	0.08	21.63	
18-25	196	4.55	2.38		Heart disease	362	8.02	12.25	
25-34	399	9.04	4.08		Asthma	25	0.36	1.40	
35-44	532	11.86	5.98		Cancer	337	6.99	11.39	
45-54	865	18.04	9.58		Dementia	511	10.89	11.39	
55-64	1314	26.21	12.70		Developmental disability	172	4.04	11.62	
65+	1612	30.30	23.62		Diabetes	265	4.73	22.37	
Race				<0.0001	Injuries	278	5.58	13.95	
White only non-Hispanic	2951	66.52	10.50		Mental illness	228	5.94	12.21	
Black only non-Hispanic	71	1.57	15.61		Old age	720	14.31	12.63	
Asian only non-Hispanic	358	5.03	12.74		Others	1228	28.44	12.96	
Hispanic	613	13.90	22.14		CLRD	140	3.08	17.83	
Others	819	12.97	18.07		Substance use	27	0.36	33.39	
Employ				<0.0001					
Employed for wages	1957	41.17	4.57						

¹ The sample size in the total and subgroups may differ due to missing data. CLRD - Chronic Lower Respiratory Disease

Most caregivers reported being over 44 years of age (N=3,791; 74.52%), were female (N=3,062, 61.63%), and identified ethnically as white only, non- Hispanic (N=2,951, 66.52%) were White only, non- Hispanic. Few caregivers reported complete NUI (N= 721, 14.71%), meaning that the majority of respondents had used the internet in the past 30-days. Caregivers predominantly provided care for patients with chronic illnesses associated with aging (e.g., dementia; N=720; 14.31%). About 2,752 (59.53%) of the respondents provided informal care for 0-8 hours weekly, and 1,487 (30.06%) have been providing care for more than 5 years.

NUI by patient's health problem. Caregivers who reported the highest proportion of NUI in the past 30 days were those of substance use (33.39%); diabetes (33.37%); Human immunodeficiency virus- HIV (21.63%) and chronic respiratory disease (17.83%) patients. However, use of the internet was reported more by caregivers of asthma (98.62%); cancer (88.61%) and dementia (88.61%) patients.

NUI by caregiver burden. In comparison with those who cared for 0-8h; caregivers who cared for 20- 39h reported higher odds of NUI (Odds ratio [OR] =1.67, 95% Confidence interval (CI) = 1.15 - 2.43) as well as those who cared for ≥40h (OR=2.62, 95%CI[1.96, 3.49]). Caregivers for ≥5 years also report- ed higher odds of NUI (OR=1.52, 95%CI[1.14, 2.02) compared to those who have cared for 0-6 months. After adjusting for sociodemographic characteristics (Model 1), these relationships remained significant for those who cared for 20-39h (adjusted odds ratio [aOR] =1.56, 95%CI[1.01, 2.43]; ≥40h (aOR=2.30, 95%CI[1.62, 3.26) and ≥5 years (aOR=1.47, 95%CI[1.06, 2.05). Also, in Model 2, caring for ≥40h remained significantly associated with higher odds of NUI (aOR=1.61, 95%CI[1.11, 2.34]) while caring for ≥5 years remained positive but not statistically significant (aOR=1.28, 95%CI[0.88, 1.86]).

Table2. Adjusted and Unadjusted Odds Ratio

	OR	95% CI	Model 1[a]		Model 2[b]	
			AOR	95% CI	AOR	95% CI
Hours Spent caring						
0-8 h	1.00		1.00		1.00	
9-19 h	1.00	0.69-1.42	1.08	0.73-1.60	1.20	0.78-1.84
20-39 h	1.67*	1.15-2.43	1.57*	1.01-2.43	1.40	0.86-2.28
≥40 h	2.62*	1.96-3.49	2.30*	1.63-3.26	1.61*	1.11-2.34
Caring length						
0-6 mo	1.00		1.00		1.00	
6 mo-2yr	1.32	0.95-1.83	1.34	0.91-1.96	1.29	0.84-1.99
2-<5yr	1.32	0.95-1.83	1.13	0.78-1.65	0.99	0.64-1.54
>5yr	1.52*	1.14-2.02	1.47*	1.06-2.05	1.28	0.88-1.86

Note: OR = odds ratio; AOR = Adjusted odds ratio; CI = confidence interval
*P<0.05
[a.] Model 1 was adjusted for sex, age, and race/ethnicity.
[b.] Model 2 was adjusted for sex, age, and race/ethnicity, education, income and employment status.

DISCUSSION

Caregiver characteristics. Caregivers reported providing care for care recipients mostly with illnesses associated with aging patients (e.g., dementia). This is not surprising as the increase in life expectancy has been shown to contribute to many older adults living with slowly-progressing life-limiting diseases (Frits, Ana, Francesca, & Jérôme, 2011). NUI in the past 30 days was reported by 14.31% of the caregivers and most of the caregivers provided care for 0-8 hours, while care- givers spending 20-39 hours caring for a loved one reported higher rates of NUI.

NUI by patient's health problem. Unlike care- givers of asthma, cancer and dementia; caregivers of substance use, diabetes, HIV and chronic respiratory disease patients reported higher NUI. This finding is supported by other studies that have found high internet use among caregivers of cancer patients (Lapid et al., 2015). In another study on disease progression among dementia caregivers, internet use rose markedly from 14% in early stage, to 67% in middle stage, ending at 100% in late stage caregiving (DiZazzo-Miller, Pociask, & Samuel, 2013), rising in use as the disease progresses. Further study is needed to understand reasons for NUI among the population of caregivers identified as low users in this study. In the general population, the non-use has been found to be attributed to reasons such as *(i) lack of access to the computer/computer connected to the internet (ii) not knowing how to use the internet (iii) being uncomfortable using the internet (iv)not knowing how to type etc.* (Kruse et al., 2012)*;* there is need to understand the contextual reasons for this sub-groups of informer caregivers.

NUI by caregivers' burden. We found caring for ≥40h to be associated with NUI even after controlling for sociodemographic factors and SES. Also, caring for ≥5 years alongside SES was associated with NUI. Ac- cording to the Role Theory, the demands of caregiving (demonstrated in the uptake of multiple roles) have been shown to negatively impact the caregiver's wellbeing; leaving them with little or no time for other things (Lee & Tang, 2015). It is important to understand how objective burden is mediated to result in NUI.

Practical Implications

These findings provide support to health care providers in identifying caregivers who are least likely to access Internet-based resources (e.g. patient portals, caregiving classes) and emphasize why resources should meet the needs of highly burdened caregivers of chronic disease patients. Further, identifying ways in which patients gain steady access to the internet (e.g., mobile phones) may improve uptake of health interventions for particular caregivers.

Future Study

      Further study is needed to examine multiple dimensions of caregiver burden (economic, subjective, psychological, etc.) and how they synergistically work to influence the NUI.

Conclusion

      Caregivers of substance use patients reported the highest NUI. Also, high objective caregiver burden is associated with non-use of the internet. Although caregivers spent longer hours with the care recipients, it still did not equate to them assessing the internet.

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