

The Pennsylvania State University

The Graduate School

College of Medicine

**THE INTERNET AS A RESOURCE FOR HEALTH INFORMATION AMONG CHRONIC  
KIDNEY DISEASE PATIENTS**

A Thesis in

Public Health Sciences

by

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## ABSTRACT:

**Background:** The Internet has become increasingly popular as a source of medical information as more patients “go online.” The degree of the Internet access among chronic kidney disease (CKD) population has not been reported.

**Objective:** To determine CKD patients’ access to the Internet and to evaluate their perceptions of the quality of this information.

**Methods:** Cross sectional self-administered survey among CKD patients and internal medicine patients recruited during routine outpatient visits to University clinics in Hershey, PA.

**Results:** A total of 133 surveys from patients attending nephrology clinic, and 85 from internal medicine were included. Among nephrology patients, the mean age of respondents was 65 years, 18.8% had greater than a high school education and the majority were Caucasian (91%). 74% of Nephrology respondents reported having Internet access. Compared to the respondents from internal medicine clinic, Nephrology respondents were older and less likely to be employed, to have high income, advanced education, Internet access, or own a smart phone. In addition, they were less likely to search for health information online and to communicate with their providers by e-mail. Of the Nephrology respondents with Internet access, 72 (77.4%) reported searching for medical information within the previous 12 months, and the majority thought that finding health information was easy and reliable. Only 7.2% were advised to visit specific websites by their providers and more than half did not discuss the searched information with their providers.

**Conclusion:** Internet access and the use of the Internet to search for health information are relatively common among CKD patients. Providers should be aware of this source of health information, be prepared to guide their patients to reliable websites and discuss any possible sought information.

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## INTRODUCTION:

### Background:

Chronic kidney disease (CKD) is a growing epidemic; over 20 million Americans have some form of chronic kidney damage (1). National guidelines for the management of chronic kidney disease recommend specific lifestyle modifications and pharmacologic therapy to prevent disease progression. Several factors may impact compliance with these guidelines, including the patient's ability to understand disease-related information and instructions from healthcare providers. Access to various resources of information can improve understanding of health information and reiterate important aspects of chronic disease management. The Internet is an important resource of medical information for patients and has become increasingly popular as more patients "go online". It is estimated that more than 75 million adults use the Internet to research health information and/or health-related products or to communicate with providers (2).

Patient-provider relationships are changing, and medical providers face new challenges as patients obtain health information from the Internet, share their experiences through social media, use health related smart phone health applications, and potentially turn to the Internet instead of consulting a health care provider.

Several studies have looked at Internet usage for health information. In 2009, the Pew Internet and American Life Project reported that 74% of adults in the United States use the Internet (3). The report suggested that 61% of these adults searched for health information and 49% accessed websites designed for a single specific medical condition. Many studies have been done exploring patient use of the Internet, specifically in primary

care (4, 5), gastroenterology (6, 7), oncology (8), genetic clinics (9) surgery (10-12), rheumatology (13), and fertility clinic (14) among others. The degree of Internet access among chronic kidney disease population has not been reported. We investigated chronic kidney disease patients' access to the Internet, the impact of demographic factors on the access to the Internet, the extent of Internet use for health care, and patients' perceptions of the quality of this information.

## SIGNIFICANCE AND AIMS:

The Internet has attracted considerable attention as a means to improve health and health care delivery. While there are concerns regarding misinformation, and potential difficulties with the confidentiality of personal information, the Internet appears as a potentially powerful and important tool for patient education.

### AIM 1)

To determine the prevalence of access to the Internet among patients with chronic kidney disease, and to explore associations of demographic factors with Internet access.

### AIM 2)

To determine the categories of medical information searched online, and to evaluate patients' perceptions of the quality of this information.

### AIM 3)

To determine the perceptions of patients towards provider-guided use of the Internet for health-related information and alternative means of communication.



## METHODS:

The cross-sectional self-administered survey was distributed to patients 18 years of age or older from the waiting rooms of the chronic kidney disease, and general internal medicine University clinics in Hershey, PA from August 2012 to February 2013. A cover letter introduced the purpose of the survey and asked the readers to participate by completing all relevant questions. Upon completion, the surveys were returned to the clinic staff.

Demographic information such as age, sex, race, occupation, marital status, level of education, and annual income were obtained. Questions were asked to determine patients' awareness of their medical conditions and kidney problems. Several questions evaluated the use of the Internet. Patients' perceptions of the reliability of the electronic health information resources were also reviewed.

Subjects were divided into respondents from renal and internal medicine clinics, respectively. The data were first summarized with frequency distributions. Proportions were generated for demographic characteristics. The descriptive characteristics of respondents of renal and internal medicine clinic were compared with *t test* for continuous variables, and *chi square of fisher test* for categorical variables as appropriate. Then, we stratified the renal clinic respondents into two groups for analysis. Group one included patients without access to the Internet, and group two included patients who had access to the Internet. Independent variables were examined as above. For multivariate analysis, we generated a multivariable logistic regression model to determine the independent contribution of patient demographic predictors of internet access in renal clinic. The model was adjusted for age, race/ethnicity, marital status, and level of education. Variables that

had less than 5 responses (annual income, employment status) were not entered into the model. We used generalized estimating equations to account for the correlation among responses by individual respondents. Statistical significance was defined as  $p < .05$ , all tests are 2-sided, and CIs were defined as 95%. Analyses were conducted using SAS software, version 9.3.

## RESULTS

A total of 139 surveys were collected from the renal clinic. 6 surveys were marginally completed and were excluded. Therefore, only 133 surveys from the renal clinic were included (Table 1). Two surveys had a lack of response to the question about access to the Internet, thus 131 surveys were used for univariate and multivariate analysis. From the internal medicine clinic, 85 surveys were collected (see table 1).

For the renal clinic, the mean age was 65 years, 42 % of respondents were men, 18.8 % had education higher than high school, and 29% had annual income more than \$ 50,000. The majority of patients were Caucasians (91%), and approximately three quarters had internet access, owned a cell phone, and were interested in communications with their providers by email. Approximately one third of the patients were unaware of the cause of their kidney disease or the severity of their kidney dysfunction.

Respondents from the renal clinic compared to the respondents from internal medicine clinic were more likely to be men and older. Respondents from the renal clinic were less likely to be employed, and less likely to have annual income > \$50,000, college education, internet access, cell phone or smart phone use. In addition, they were less likely to search for health information online, and less likely to communicate with their providers by e-mail.

	Renal Clinic (n=133 )	IM Clinic (n=85)	P Value
<b>Age (in yrs)</b>	65 (SD:16.6)	51.5 (SD:16.5)	<.0001
<b>Sex (Male)</b>	75 (57.25 %)	15 (17.65%)	<.0001

<b>Employment</b>	Employed	24 (18.80 %)	53 (63.86%)	<.0001
<b>Marital Status</b>	Married	86 (65.41%)	55 (64.71%)	0.9148
<b>Education</b>	College and higher	66 (51.91%)	64 (75.29%)	0.0006
<b>Annual Income</b>	>\$ 50,000	33(28.95%)	44(62.86%)	<.0001
		Missing var= 19	Missing var=15	
<b>Race</b>	Caucasian	112 (91.20%)	65 (84.42%)	0.1404
<b>Smoking</b>	Active smoker	11 (8.40%)	13 (15.48%)	0.0995
<b>Seek information from others</b>		22 (17.19%)	26 (35.62%)	0.0032
<b>Internet access</b>		98(74.81%)	75 (89.29%)	0.0043
<b>Searching health info</b>		72 (77.42%)	68 (87.18%)	0.0007
<b>Having smart phone or tablet?</b>		30 (23.81%)	48 (58.54%)	<.0001
<b>Using Health related app</b>		8 (6.45%)	14 (23.73%)	0.0008
<b>Having Cell Phone</b>		100 (78.74%)	78 (96.30%)	0.0004
<b>Using health related videos on Youtube</b>	Never	94 (80.34%)	48 (62.34%)	0.0183
<b>Interested in communication by email</b>		78(78%)	70(92%)	0.0156

Table 1: Demographic features of respondents from renal and internal medicine clinic. Data presented as: n (column percentage).

	Total sample (n=133 )	Group 1 No access to web (n=33)	Group 2 Access to web (n=98)	P value
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<b>Age (in yrs)</b>		65 (SD:16.6)	75	61	<.0001
<b>Sex (Male)</b>		75 (57.25 %)	14 (42.42%)	61 (62.24%)	0.0465
<b>Employment</b>	Employed	25 (18.80 %)	1 (3.03%)	23 (23.47%)	0.0081
<b>Marital Status</b>	Married	87 (65.41%)	12 (36.36%)	74 (75.51 %)	<.0001
<b>Education</b>	College and higher	68 (51.91%)	6 (18.18%)	60 (62.50%)	<.0001
<b>Annual Income</b>	>\$ 50,000  (missing var= 19)	33(28.95%)	1(4.00%)  8 missing	32(36.78%)  11 missing	0.0015
<b>Race</b>	Caucasian	114 (91.20%)	25(80.65 %)	87(94.57%)	0.0188
<b>Smoking</b>	Active smoker	11 (8.40%)	3 (7.14%)	8(9.09%)	0.6283
<b>Awareness of the cause of kidney disease</b>	Do not know	35 (28.93%)	9(30%) 3 missing	26 (28.57%) 7 missing	
	Know	86(71.07%)	21(70.0%)	65(71.43%)	0.8810
<b>Awareness of the stage of disease</b>	Don't know	54 (41.86%)	16 (51.61%)	38 (38.78%)	0.2067
<b>Seek information from others</b>		22 (17.19%)	4 (12.12%)	18 (18.95%)	0.3706
<b>Smart Phone or tablet?</b>		30 (23.81%)	1(3.33%)	29(30.85%)	0.0022
	Health app	8 (6.45%)	0	8 (8.60%)	

<b>Cell Phone</b>	100 (78.74%)	16(50%)	84(90.32%)	<.0001
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Table 2: Demographic features of respondents, stratified by access to the internet in the renal clinic. Data presented as: n (column percentage).

Internet access among the renal clinic respondents

Renal clinic respondents were stratified into two groups: group 1 with no Internet access, and group 2 with Internet access ( see table 2). In comparison to group 1, group 2 subjects were: younger (p <.0001), completed higher levels of education (p <.0001 %), more likely to be employed (p = 0.0087), more likely to be married (p <.0001), more likely to be Caucasian (p = 0.0188), and more likely to have cell phone (p < 0.001) or smart phone (p=0.0022).

Among subjects with a college education or higher, over 90 % had Internet access, whereas, 57 % of subjects with high school or less had Internet access; among employed subjects, over 95 % had internet access while 70% of non-employed had Internet access. 78% of the Caucasians and 46% of non-Caucasians had Internet access.; Among patients with income of \$ 50,000 and higher, 97% had access to the Internet, while 70 % of those with income of less than \$ 50,000 had access to the Internet.

Of the 98 subjects with Internet access, 72 (77.42%) reported searching for medical information within the previous 12 months. Therefore, more than half (57.48%) of the entire sample searched the Internet for medical information in the previous 12 months.

The characteristics of the online information searched

Among renal clinic respondents, the following categories were searched (see table 3): kidney disease (59.4%), cost and side effects of medications (56%), treatment of kidney

disease (42%), dietary treatment (33.7%), herbal treatment (20.2 %), and support organizations (9%).

Most patients who searched the Internet for health information found searching useful, easy, and reliable. Half of these patients rarely or never discussed the searched information with their physicians. 7.2 % of respondents from CKD clinics, and 5.7% from internal medicine clinics had been advised to visit specific disease-related websites.

		<b>Renal Clinic</b>	<b>IM Clinic</b>
<b>Searched the Internet for Health information</b>		72 (77.42%)	
<b>Categories of Searched Information</b>	Kidney disease	44 (59.46%)	
	Medications (cost, side effects)	42 (56.00)	
	Treatment of kidney disease	31 (41.89%)	
	Dietary	25 (33.78%)	
	Health foods or herbal treatments	15 (20.27%)	
	Support Organizations	7 (9.46%)	
<b>Usefulness</b>	Useful or very useful	70 (92.2%)	64 (92.75%)
<b>Easiness</b>	Easy	67 (89.33%)	65 (90.28%)
<b>Reliability</b>	Very and Usually reliable	38 (49.35%)	46 (65.71%)
	Sometimes reliable	35 (45.45%)	22 (31.43%)
	Searching easier than consulting provider	23 (30.26%)	39 (57.35%)
<b>Start or stop a med (internet)</b>	<b>Never</b>	74 (93.67%)	58 (80.56%)
<b>Discussion with provider</b>	Yes ( always and sometimes)	35(54.3%)	35 (48.61%)

	Rarely	29 (36.71%)	22 (30.56%)
	Never	15 (18.99%)	15 (20.83%)
<b>Advised use of the internet</b>		7 (7.29%)	4 (5.71%)
<b>How often if provided</b>	Very often and often	51 (60%)	42 (62.69%)
<b>Communicate by email</b>		63 (71.59%)	61(82.43%)

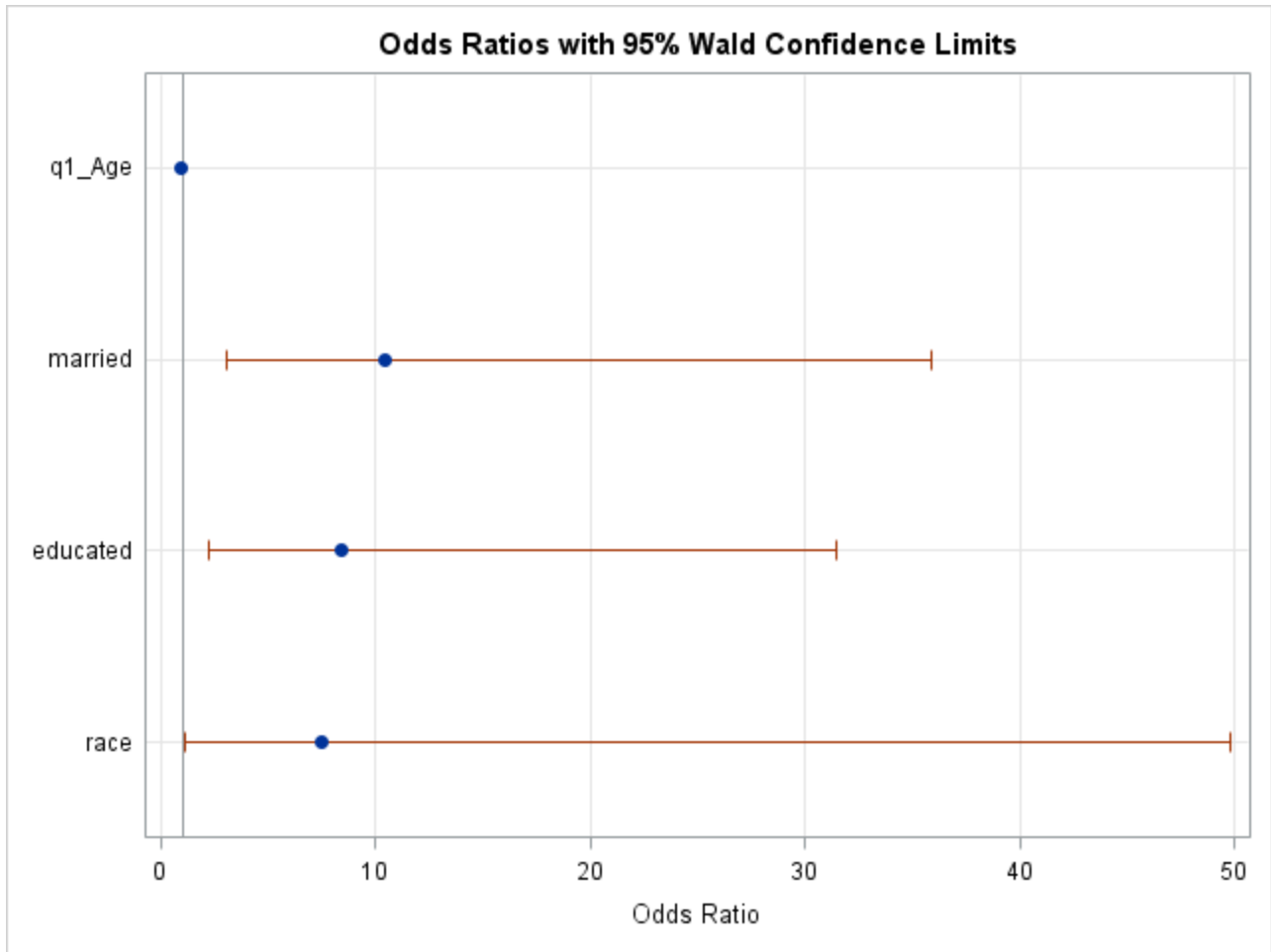
Table 3: Categories of medical information sought online, and characteristics of medical search.

Among renal clinic respondents, multivariate analysis was performed using stepwise logistic regression. The outcome variable was access to the Internet (table 4, 5, and figure 1). The model was adjusted for: age, marital status, education, race. The adjusted model showed that individuals with access to the Internet, compared to subjects without Internet access, were more likely be younger (OR: 0.908; 95% CI: 0.828–0.964, P=0.001), married (OR: 10.422; 95% CI: 3.024–35.92, P <.0001), with at least college education (OR: 8.146; 95% CI: 2.25 – 31.43, P = 0.001), and Caucasian (OR: 7.44; 95% CI: 1.1 – 49).

Odds Ratio Estimates and Wald Confidence Intervals				
Variable	Estimate	95% Confidence Limits	P value	
Age	<u>0.908</u>	0.828	0.964	<0.001
Married	<u>10.422</u>	3.024	35.92	<.0001
College education or higher	<u>8.416</u>	2.25	31.43	<0.001
Caucasian	<u>7.440</u>	1.112	49.79	0.0290

Table 4: Odds ratio, confidence intervals, and p value for patients with access to the Internet compared to patients without access using the adjusted model of logistic regression.





Graph 1: Graph of odds ratio in the adjusted model of log regression.

## Discussion

In the patient's surveyed, more than half of chronic kidney disease patients had searched the Internet for medical information during the previous 12 months. Previous studies reported that a quarter to third of their sample had searched the Internet for medical information (7, 15). However, those studies were done among different patient populations (internal medicine and gastroenterology clinics). In another survey study among subjects from primary care clinics, Internet use for medical search was 53% (REF #16). However, the population of the latter study was different from ours as well, as the mean age was 45, and more than half had high income (16).

The differences between the respondents from renal clinic and internal medicine clinic might be related to the difference in the population, as the renal clinic patients were older, less educated and with lower annual income. We could not assess whether chronic kidney disease itself was a factor in the difference in the access to the internet and other covariates.

Only 7 subjects out of 133 were referred by a physician or physician's office to a certain website, which is consistent with the finding of a telephone survey by Cyber Dialogue conducted nearly fifteen years ago (15). This finding might suggest that over time, the practice by physicians of encouraging patients to seek medical information from the internet has not changed significantly. The low rate of referral of patients by physicians to seek medical information from the Internet might be due to a persistent misconception among physician's that patients have minimum access to the Internet or electronic resources. An additional or alternative reason might be the assumption that patients will not be interested in further information or resources outside the clinics. A national survey

of the United States physicians showed that physicians are often not receptive to discussing internet information with their patients (17). In our study, 60% of patients would search the Internet if their physician provided guidance to a specific website for health information. Medical students and trainees should be made aware of the utility and limitations of these alternative sources of information in patient care.

Because of the unregulated nature of the Internet, the quality of its medical information is variable. As many as 94% of patients perceived the information as being reliable, and almost half would rarely or never discuss information obtained online with their physicians. Not discussing information obtained online with physicians may suggest that the obtained information is already accepted as clear and reliable. This places the physician at a position of responsibility in leading the search and helping guide patients to reliable websites, and encouraging patients to discuss searched information with health care providers.

One limitation of our study is the limited population sampled. The population was elderly with mean age of 65, as well as Caucasian and from a lower income category. In addition, this study was performed at a single site in a suburban community at clinics of an academic medical center. Results may not be generalizable to more diverse populations or practice settings. Our results also limited by the self-reported nature of the survey.

Further studies are needed to evaluate the impact that Internet guidance by physicians may have on management of chronic kidney disease and if access to the Internet would increase patient health literacy and treatment compliance. Ultimately, further studies will be needed to see how the Internet can be used as a resource to improve management of chronic kidney disease.

## Conclusion

We found that Internet access and the Internet use for health information was relatively common among CKD patients. Internet access was less common among poor, under educated and non-Caucasian CKD patients. Although CKD patients frequently used the Internet for health information, they rarely discussed this information with their physician. In addition, CKD patients were rarely encouraged to visit specific sites for health information by their health care providers.

Physicians should be aware of this resource of health information for patients and be prepared to provide specific direction toward reliable websites. They should be prepared to discuss any possible information or questions. This might lead to better understanding of the nature of kidney disease and better decision making. Providers should consider the lack of access to the Internet among their patients and be able to suggest alternative tools of education.

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