Expanding access to high-quality plain-language patient education information through context-specific hyperlinks

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ABSTRACT

Medical records, which are increasingly directly accessible to patients, contain highly technical terms unfamiliar to many patients. A federally qualified health center (FQHC) sought to help patients interpret their records by embedding context-specific hyperlinks to plain-language patient education materials in its portal. We assessed the impact of this innovation through a 3-year retrospective cohort study. A total of 12,877 (10% of all patients) in this safety net population had used the MPC links. Black patients, Latino patients comfortable using English, and patients covered by Medicaid were more likely to use the informational hyperlinks than other patients. The positive association with black race and Latino ethnicity remained statistically significant in multivariable models that controlled for insurance type. We conclude that many of the sociodemographic factors associated with the digital divide do not present barriers to accessing context-specific patient education information once in the portal. In fact, this type of highly convenient plain-language patient education may provide particular value to patients in traditionally disadvantaged groups.

BACKGROUND

Providing patients with access to their medical records became a national priority with the federal electronic health record incentive program (the "meaningful use" program) mandating various forms of electronic release of data to patients (1-3). To provide patients with records access, healthcare institutions typically offer patient portals, web-based products that give patients access to data from the electronic health record (EHR) (4-7).

However, because medical records are created for medical professionals, they contain technical vocabulary that tends to be unfamiliar to patients, including medication names, diagnoses, and procedures. This vocabulary is particularly challenging for patients with low levels of health literacy (8-10), which has been defined as the ability to obtain, understand, and communicate about health-related information to make informed decisions (10). Low health literacy is associated with increased rates of hospitalization, lower use of preventive care, and among the elderly, worse overall health status and higher mortality (10-12). One-quarter to one-third of Americans are estimated to have limited health literacy, and it is more prevalent among racial and ethnic minorities, the elderly, and those living in poverty (12-14). As a result, many of the patients most in need of information about their health are among those least likely to be able to use it (15).

One potential solution is to provide plain-language explanations of difficult medical terms in context. A precedent is found in the infobutton, a clinician-facing innovation that provides context-specific information in the EHR, which has been shown to help clinicians answer clinical questions quickly at the point of care (16). To provide infobutton-like resources for patients, the National Library of Medicine recently collaborated with EHR vendor Epic Systems Inc. and the Institute for Family Health (IFH), a federally qualified health center. The 3 collaborating institutions developed a service hyperlinking vocabulary terms in the Epic portal with MedlinePlus, the National Library of Medicine's free online patient education resource (www.nlm.nih.gov/medlineplus). MedlinePlus is an encyclopedia of plain-language explanations of medical diagnoses, medications, and other medical terms, designed to be at the 8th-grade reading level. The service, MedlinePlus Connect, automatically renders medical terms in the electronic patient portal as active hyperlinks. Notably, by hyperlinking unfamiliar terms directly to related information in MedlinePlus, this service helps patients access relevant information without the additional barrier of using a search engine, and without encountering the irrelevant or low quality results that might be produced by a self-directed online search. The service, first implemented at IFH, is now available as a web service and has been implemented in other electronic health record and electronic patient portal systems across the country (https://www.nlm.nih.gov/medlineplus/connect/service.html).

In this study, we sought to evaluate uptake of the innovation by tracking use of the vocabulary hyperlinks by patients over the first 3 years of the service. We hypothesized that use of these vocabulary hyperlinks would be lower among the disadvantaged patient groups affected by the "digital divide" (17).
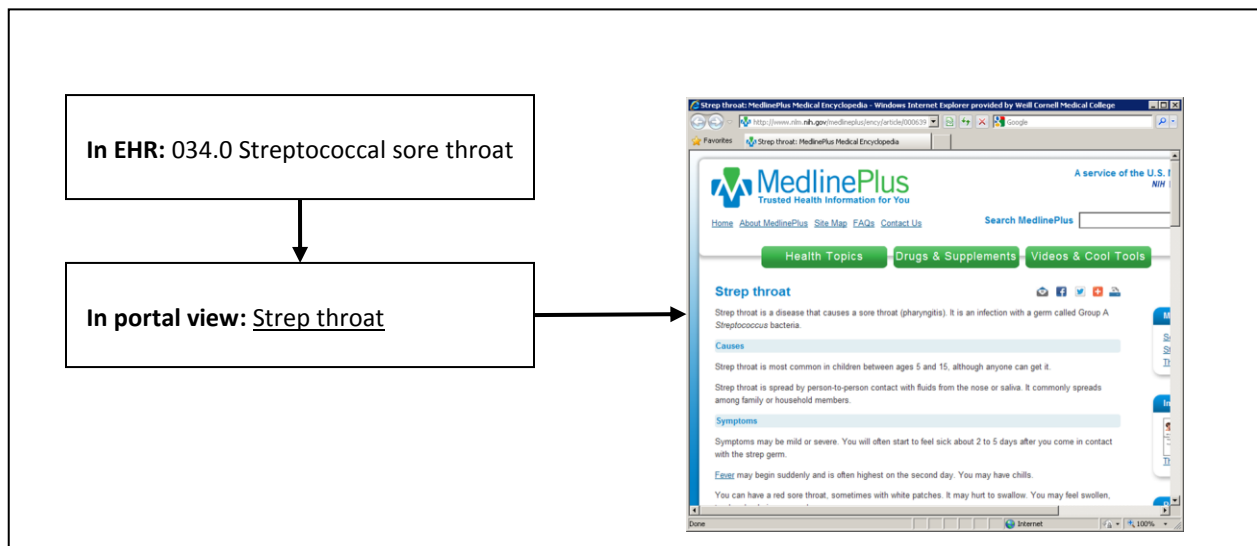
Figure 1: The ICD term in the EHR problem list or billing code is rendered in the patient portal as the ICD term or substituted with a more familiar term. With MedlinePlus Connect (MPC), the term is automatically rendered as an active hyperlink, with the ICD number embedded in URL. Clicking on the term produces a pop-up window with the corresponding MedlinePlus information.

METHODS

Setting: The Institute for Family Health is a federally qualified health center with 18 sites in Manhattan and the Bronx, as well as clinics in rural areas and smaller towns to the north of the city in the Hudson Valley. Almost all physicians are family practice physicians. An early adopter of EHRs, IFH has offered its patients an English-language electronic patient portal (MyChart) since 2007, with the Spanish-language version added in 2011.

When patients log into their portal account, they can see the conditions listed on their EHR problem list as well as the billing codes from each encounter. Some of these medical conditions are rendered directly as ICD terminology, and a subset are rendered as as "patient-friendly" equivalents (e.g., "strep throat" instead of "streptococcal infection of the throat").

With MedlinePlus Connect (MPC), all of these medical conditions and procedures are automatically rendered as active hyperlinks. Each hyperlink contains the ICD code associated with the medical term, and automatically links to the most relevant MedlinePlus information, which is also indexed by ICD code. Data collection for this study was conducted before IFH transitioned to ICD-10, so all codes were ICD-9.

Study design and data collection: For this retrospective cohort study, all adult patients with a visit to an IFH site between February 2011 and February 2014 were eligible. The primary outcomes were frequency of patient portal access and frequency of use of MPC. For the predictor variables, deidentified reports of patient data were generated from the Epic database and included age, gender, race, ethnicity, insurance status, preferred language, location, number of clinic visits, and encounter diagnoses (during the course of this study, these were ICD-9 codes). We applied the Johns Hopkins Adjusted Clinical Groups algorithm to the ICD-9 codes to classify patients by number of chronic conditions. We attributed each patient to the provider he or she saw the most frequently (his/her "preferred" provider). As an indicator of the provider's IFH-specific workload, we produced a count of all patients seen by that provider. The project was approved by the IRBs of Weill Cornell and the Institute for Family Health.

Analysis: Patient characteristics were summarized with descriptive statistics, and assessed for association with (A) portal use and (B) MPC use in bivariate analyses using chi-squared tests or independent sample t-tests as appropriate. We constructed multivariable logistic regression models for MPC use among patient portal users only. Model 1 incorporated variables that were significant at .05 in the bivariate analyses (with the exception of number of chronic conditions, which was so strongly correlated with number of encounters that it raised collinearity concerns and was omitted). Region was not included as it was not a significant predictor in bivariate analyses. However, because of the marked differences in the demographic profile of the 3 regions, we also constructed exploratory

multivariable models stratified by region. These models (not shown) revealed a significant interaction between age and region, with age having different effects on MPC use in different regions. We therefore constructed multivariable Model 2 containing all variables included in Model 1 plus region and a region x age interaction term. After confirming that the Akaike information criterion (AIC) for Model 2 was smaller than the AIC for Model 1 suggesting improved fit, we selected Model 2 as the final model for the current paper.

For exploratory purposes, we also computed a "popularity" index for each vocabulary term that was clicked by the patients. This "popularity" index was the number of patients who clicked the term divided by the number of patients in whose medical record the term appeared. To simplify the graph (figure 1), we reduced the number of vocabulary terms by running the ICDs through the AHRQ/HCUP Clinical Classifications grouper, which groups closely related ICD-9 codes into clinical conditions (e.g., diabetes, endometriosis, etc.).

RESULTS

There were 129,738 adult patients with one or more clinical visits in the study period; 30,692 (24%) had portal accounts. A total of 12,877 (42% of portal users, or 10% of all patients) explored one or more MedlinePlus Connect links. Patients who used the vocabulary hyperlinks clicked a median of 2.0 times (maximum: 97) and a median of 2.0 different terms (maximum, 24). As we have reported elsewhere, portal users were representative of the entire IFH population in terms of racial distribution but were more likely to be privately insured (18).

Table 1: Characteristics of MedlinePlus Connect (MPC) users and nonusers

Characteristic		Total (Column %)	Portal users (Row %)	MPC users as % of portal users (Row %)	MPC non-users as % of portal users (Row %)	P	MPC users as % of all patients in category (Row %)
N		129,738 (100)	30692 (23.7)	12877 (42.0)	17815 (58.0)		12877 (9.9%)
Age	18-24	24051 (18.5)	6195 (25.8)	2436 (39.3)	3759 (60.7)	< .001	10.1%
	25-44	56414 (43.5)	15702 (27.8)	6608 (42.1)	9094 (57.9)		11.7%
	45-64	38921 (30.0)	7526 (19.3)	3338 (44.4)	4188 (55.7)		8.6%
	65+	10352 (8.0)	1269 (12.3)	495 (39.0)	774 (61.0)		4.8%
Gender	Women	78698 (60.7)	20708 (26.3)	9034 (43.6)	11674 (56.4)	< .001	11.5%
	Men	51035 (39.3)	9984 (19.6)	3843 (38.5)	6141 (61.5)		7.5%
Race	Black	29774 (23.0)	6752 (22.7)	2910 (43.1)	3842 (56.9)	< .001	9.8%
	White	46417 (35.8)	11670 (25.1)	4701 (40.3)	6969 (59.7)		10.1%
	All other	33224 (25.6)	7926 (23.9)	3426 (43.2)	4500 (56.8)		10.3%
	Unknown	20323 (15.7)	4344 (21.4)	1840 (42.4)	2504 (57.6)		9.1%
Ethnicity by language preference	Latino, prefers Spanish	10080 (7.8)	1125 (11.2)	363 (32.3)	762 (67.7)	< .001	3.6%
	Latino, not prefer Spanish	25002 (19.3)	7116 (28.5)	3213 (45.2)	3903 (54.9)		12.9%
	Not Latino	79141 (61.0)	19517 (24.7)	8084 (41.4)	11433 (58.6)		10.2%
	Unknown	15515 (12.0)	2934 (18.9)	1217 (41.5)	1717 (58.5)		7.8%
Insurance	Private	38885 (30.0)	13035 (33.5)	5567 (42.7)	7468 (57.3)	< .001	14.3%
	Medicaid	39706 (30.6)	9083 (22.9)	3959 (43.6)	5124 (56.4)		10.0%
	Uninsured	28695 (22.1)	4395 (15.3)	1572 (35.8)	2823 (64.2)		5.5%
	Medicare	15478 (11.9)	2266 (14.6)	976 (43.1)	1290 (56.9)		6.3%
	Unknown	2474 (1.9)	427 (17.3)	174 (40.8)	253 (59.3)		7.0%
	Other public or dual	4500 (3.5)	1486 (33.0)	629 (42.3)	857 (57.7)		14.0%
Encounters	>3	68850 (53.1)	21522 (31.3)	10182 (47.3)	11340 (52.7)	< .001	14.8%
Chronic conditions	1 or more	67815 (52.3)	17745 (26.2)	8439 (47.6)	9306 (52.4)	< .001	12.4%
Region	Hudson Valley	38016 (29.3)	5344 (14.1)	2272 (42.5)	3072 (57.5)	.60	6.0%
	Bronx	24631 (19.0)	6486 (26.3)	2729 (42.1)	3757 (57.9)		11.1%
	Manhattan	67090 (51.7)	18862 (28.1)	7876 (41.8)	10986 (58.2)		11.7%
Workload of "preferred" provider	< 794 patients a year	32190 (24.8)	6613 (20.5)	2679 (40.5)	3934 (59.5)	<.001	8.3%
	794 – 1715	32276 (24.9)	8419 (26.1)	3540 (42.1)	4879 (58.0)		11.0%
	1716 – 2714	32130 (24.8)	7856 (24.5)	3472 (44.2)	4384 (55.8)		10.8%
	2715 or more	33142 (25.6)	7804 (23.6)	3186 (40.8)	4618 (59.2)		9.6%

Sociodemographic predictors of use of MedlinePlus Connect (bivariate)
As demonstrated in Table 1, use of the informational hyperlinks was associated with socioeconomic characteristics but not in the hypothesized direction. (Throughout Table 1, it is important to note that because of the large sample size, very small differences were sometimes statistically significant even if they are unlikely to be clinically significant.) Black patients were *more* likely to use MPC than white ones (43% compared to 40%), and Latino patients more likely to use the resource than non-Latinos (43% compared to 41%). When Latinos were further subdivided by their preferred language, it became clear that it was the English-preferring Latinos who were driving the use of this resource. Finally, patients covered by Medicaid were *more* likely to use MPC than privately insured ones (44% versus 43%).

Clinical predictors of use of MedlinePlus Connect (bivariate)
Use of MPC was associated with clinical characteristics in the expected direction. Women, patients with more encounters, and patients with more chronic conditions were more likely to use the resource. MedlinePlus Connect users were very slightly older than nonusers, due primarily to greater representation in the middle-aged (45-64 years) age bracket.

Health system predictors of use of MedlinePlus Connect (bivariate)
Patients of the least busy and most busy providers were least likely to use MPC. There were no differences by region.

Table 2: Multivariable model of MPC use by sociodemographic characteristics

Characteristic	Level	Adjusted Odds Ratio	CI		P
Age	(per 1-year increase)	1.004	1.002	1.007	*<.001*
Sex	Women	1.167	1.109	1.227	*<.001*
	Men	Reference			
Race	Black	1.100	1.027	1.180	*.007*
	All other	1.143	1.056	1.237	*<.001*
	Unknown	1.106	1.010	1.211	*.02*
	White	Reference			
Ethnicity with preferred language	Latino, does not prefer Spanish	1.077	1.001	1.159	*.045*
	Latino, prefers Spanish	0.607	0.525	0.702	*<.001*
	Unknown ethnicity	0.993	0.900	1.097	.89
	Not Latino	Reference			
Insurance	Medicaid	0.897	0.847	0.951	*<.001*
	Medicare	0.865	0.782	0.957	*.005*
	Other Public or dual	0.960	0.859	1.073	.47
	Uninsured	0.766	0.711	0.824	*<.001*
	Unknown	0.888	0.726	1.083	.24
	Private	Reference			
Encounters	>3	2.164	2.049	2.287	*<.001*
Provider workload	< 794 patients a year	1.093	1.022	1.169	*.01*
	794 – 1715	1.173	1.094	1.257	*<.001*
	1716 – 2714	1.034	0.965	1.109	.34
	2715 or more	Reference			
Region	Hudson Valley	1.019	0.841	1.235	.85
	Bronx	1.379	1.161	1.639	*<.001*
	Manhattan	Reference			
Interaction	Hudson Valley*Age	0.997	0.993	1.001	.16
	Bronx*Age	0.988	0.983	0.992	**<.001**
	Manhattan*Age	Reference			

Multivariable model of MedlinePlus Connect use
The final multivariable model included: age, gender, race, ethnicity with preferred language, insurance type, number of encounters, workload of preferred provider, region, and the region x age interaction term (Table 2). In this model, use of the informational hyperlinks remained positively associated associated with older age, female sex, black race,

English-preference Latinos, having private insurance, more clinical encounters, and provider workload (with MPC use being more common forms patients of less busy providers).

Interestingly, when we controlled for race and ethnicity in this multivariable model, patients with Medicaid were less likely to use the MPC resource. The positive relationship in the bivariate analysis was therefore due to the black and Latino patients who were using the resource. The multivariable results suggest that within each racial and ethnic category, patients with Medicaid (the lower income patients) were somewhat less likely to use the MPC resource.

As noted in the methods, we included the interaction term between region and age because we saw different age-related patterns in preliminary bivariate models that were stratified by region (not shown). These models showed that older patients were more likely than younger patients to use MPC in Manhattan but not in other regions. To confirm this finding in the multivariate models, we included an interaction term between region and age, and confirmed that it was statistically significant in the expected direction. In other words, as Manhattanites became older, they were more likely to use MPC, but this pattern was much weaker in the Bronx and not found at all in the Hudson Valley. We attribute this finding to the different demographic patterns in these regions. In Manhattan, the older population contains quite a number of people who are well-educated and have relatively high socioeconomic status, so they might be more likely to do research on their health conditions. By contrast, the Bronx and the small towns where IFH has a presence in the Hudson Valley are much less affluent, and elderly patients in those areas are likely to be less well-educated and less affluent members of minority groups.

Frequently explored terms

Diagnosis "popularity" (or proportion of times a diagnosis term was clicked) was fairly constant at an average of 14.5% regardless of how common the diagnosis was (Figure 2). "Popularity" appeared high for some of the rare conditions, but this was in fact an artifact of the rarity of the condition. For example, *multiple myeloma* had a very high popularity rating of 56%, but this was because only 9 patients had the condition and 5 of them clicked upon it.
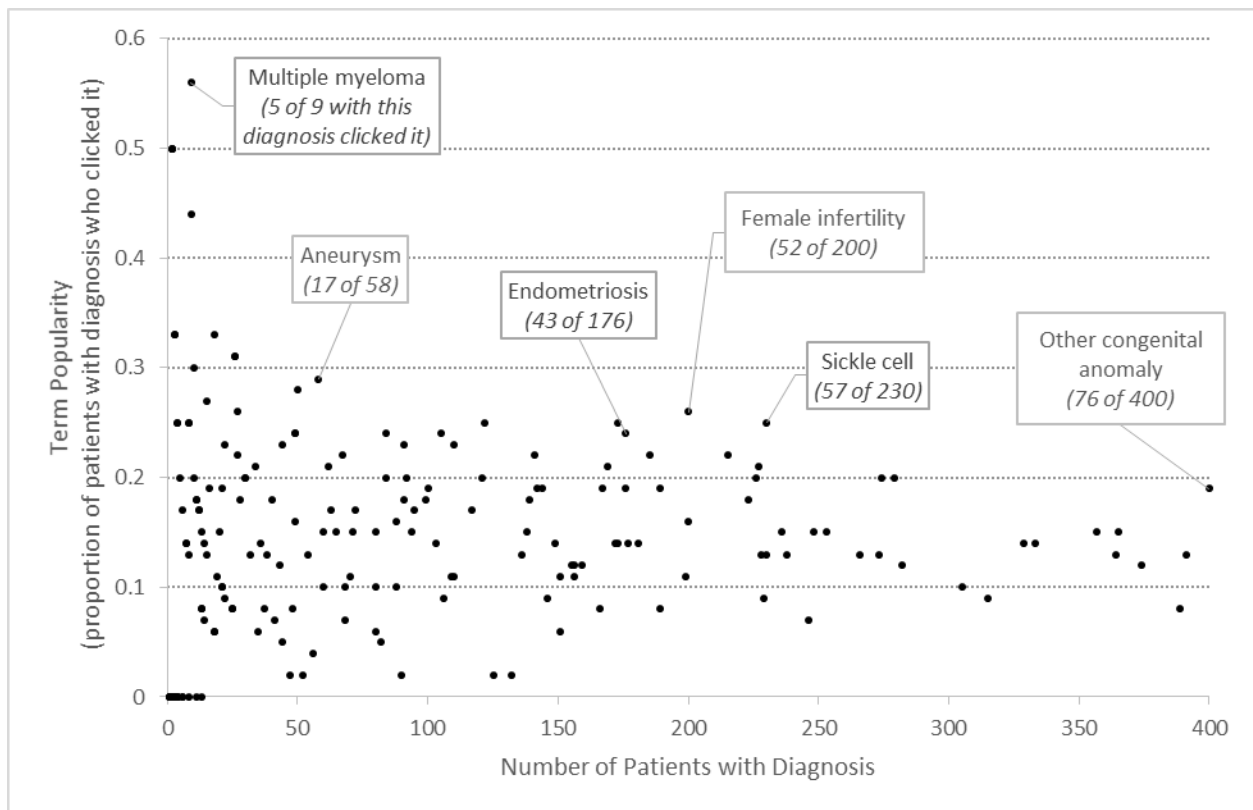

Figure 2: *Each dot represents a diagnosis. Data labels are placed on a small number of "popular" terms for illustrative purposes.*

As Figure 2 shows, there was no obvious explanation for term "popularity." To further explore "popularity," we retrieved the 10 terms that were clicked by the largest numbers of patients (Table 3). No single unifying principle is immediately apparent to explain why these terms were frequently clicked. It is possible that in some cases, it is because the terms were unfamiliar and technical ("hyperlipidemia," "unspecified essential hypertension"), prompting patients to seek a definition. It is also possible that people were more likely to click on stigmatized or contested diagnoses (e.g., "obesity," "depression," "anxiety"). In other cases, perhaps patients clicked when they were motivated to take action and do more research ("nicotine dependence," which is likely to appear in the record of the patient already being treated for smoking cessation). A better understanding of why patients seek more information about certain conditions and not others would be a fruitful avenue for future quantitative and qualitative work.

Table 3: Top 10 most explored terms

ICD9 code	Diagnosis term	Number of patients who clicked this term	Number of portal users with this diagnosis	Clickers as percent of portal users with diagnosis ("popularity")
V70.0	General adult medical examination	4638	21,940	21.1
278.00	Obesity	929	3896	23.8
V25.9	Contraceptive management	895	5471	16.4
272.4	Hyperlipidemia	619	3560	17.4
401.9	Unspecified essential hypertension	407	3027	13.5
311	Depression	358	2216	16.2
V62.9	Psychosocial circumstances	362	1560	23.2
300.00	Anxiety	317	1962	16.2
305.1	Nicotine dependence	306	2915	10.5
401.1	Benign essential hypertension	242	1749	13.8

DISCUSSION

Although providing patients with access to their medical records could help them better understand their health and healthcare, patients who do not understand the medical language found in these medical records are unlikely to benefit. Our study shows that a plain-language encyclopedia of medical terms, hyperlinked directly to the unfamiliar term, is frequently explored by patients with access to their medical records via an electronic patient portal. About 10% of all patients in this safety net population used the informational hyperlinks. The hyperlinks were appropriately used most by those with the greatest needs for medical information, i.e., those with more medical conditions and visits.

The sociodemographic analysis held some surprises. We and others have expressed concern that because of disparities in computer access as well as disparities in health literacy, any beneficial effects of patient portals are likely to be unequally distributed (19). However, counter to the main hypothesis of the current study, we found positive associations between MPC use, black race, being an English-speaking Latino patient, and being covered by Medicaid. The positive associations with black race and Latino ethnicity remained statistically significant in multivariable models that controlled for insurance type. However, in the multivariable model, Medicaid coverage developed a negative relationship with MedlinePlus Connect use. This can be interpreted to mean that Blacks and English-speaking Latinos within each insurance category are more likely to use the informational hyperlinks, although Medicaid (low income) patients are in general less likely to do so.

Latino patients who indicated that they prefer using Spanish in their clinical encounters were markedly less likely to use the resource. This was despite the availability of a Spanish-language portal and Spanish-language informational resources.

Overall, this study suggests that some of the factors associated with the digital divide which created barriers to accessing the electronic portal were not barriers to using the MedlinePlus Connect informational hyperlinks. However, the language barrier remains indicating the need for additional outreach and services to ensure Spanish-speaking patients have high-quality information about their health.

There are a number of potential explanations for why patients might click terms. One explanation is that patients with low health literacy (9, 11) would be less likely to understand a particular medical term and might be

more likely to click to find out more. Unfortunately, because we were using EHR data, we had no assessments of patient health literacy, so we cannot conclude definitively that patients with low health literacy were the ones who were clicking on the hyperlinks. However, the prevalence of low health literacy is known to be higher among minority and low income patients (9, 11), and our findings demonstrate that these groups were particularly likely to use the MPC links. If low health literacy is the explanation, this would suggest that the MedlinePlus Connect links are providing particular value to patients who have less familiarity with medical vocabulary. This could provide an explanation for certain of the most "popular" terms in Figure 2, such as *aneurysm* and *endometriosis*, multisyllabic words likely to be unfamiliar to lay audiences.

Other reasons why a patient might click a term could include being highly concerned about a diagnosis, needing more explanation than what the provider discussed, or feeling uncomfortable having an extended conversation with the provider. For example, it is possible that patients with sensitive, stigmatized, or contested diagnoses (20-22) might be interested in finding out more in private after the encounter, when visiting the patient portal. These could explain the high click rates for potentially sensitive terms such as *obesity* and *psychosocial circumstances* in Table 3, and for highly concerning diagnoses such as *sickle cell* in Figure 2.

Limitations

This was a study at a single center providing safety net care, and all patients used a single commercially available patient portal product, so generalizability to other products and populations is unknown. Analyses were limited to data available in log files or the EHR, and therefore no direct measurements of health literacy, access to computers, or patient perceptions were available. This study did not include any measurement of healthcare outcomes, so it is not known whether access to this information actually helped patients manage their own health or their healthcare.

Conclusions

Context-specific hyperlinks that provided plain-language explanations of medical vocabulary were heavily used by electronic patient portal account holders at a federally qualified health center, especially those with multiple office visits and clinical conditions. Socioeconomic factors that presented barriers to access to the portal (such as race and poverty) did not pose barriers to use of the vocabulary hyperlinks within the portal. In fact, hyperlink users were more likely to be black or English-speaking Latino than were non-hyperlink users. We conclude that context-specific medical vocabulary hyperlinks are valuable to patients with the greatest information needs because of greater use of healthcare services, and that they are of particular use to patients in disadvantaged populations.

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