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Characteristics of Patients Who Report Confusion After Reading Their Primary Care Clinic Notes Online

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Abstract

Patient access to online electronic medical records (EMRs) is increasing and may offer benefits to patients. However, the inherent complexity of medicine may cause confusion. We elucidate characteristics and health behaviors of patients who report confusion after reading their doctors' notes online. We analyzed data from 4,528 patients in Boston, MA, central Pennsylvania, and Seattle, WA, who were granted online access to their primary care doctors' clinic notes and who viewed at least one note during the 1-year intervention. Three percent of patients reported confusion after reading their visit notes. These patients were more likely to be at least 70 years of age ($p < .0001$), have fewer years of education ($p < .0017$), be unemployed ($p < .0001$), have lower levels of self-reported health ($p < .0043$), and worry more after reading visit notes (relative risk [RR] 4.83; confidence interval [CI] 3.17, 7.36) compared to patients who were not confused. In adjusted analyses, they were less likely to report feeling more in control of their health (RR 0.42; CI 0.25, 0.71), remembering their care plan (RR 0.26; CI 0.17, 0.42), and understanding their medical conditions (RR 0.32; CI 0.19, 0.54) as a result of reading their doctors' notes compared to patients who were not confused. Patients who were confused by reading their doctors' notes were less likely to report benefits in health behaviors. Understanding this small subset of patients is a critical step in reducing gaps in provider–patient communication and in efforts to tailor educational approaches for patients.

The language and framework of doctors' notes has traditionally focused on functionality for physicians, administration, billing, coding, and insurance providers, rather than direct communication with patients (Siegler, 2010); (Winkelman & Leonard, 2004). However, online doctors' notes and medical records offer clear benefits for patients: ease in accessing personal records, the ability to share records with caretakers or family members (Jackson et al., 2014), and opportunities for patients to be active participants in their own care. Patients

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Publisher's Disclaimer: OpenNotes is not a software program. OpenNotes is a national initiative that invites patients to review their visit notes written by their doctors, nurses, or other clinicians.

increasingly understand these benefits and want access to their records (Chhanabhai & Holt, 2007; Ferreira et al., 2007; Fowles et al., 2004; Pyper, Amery, Watson, & Crook, 2004). Importantly, patient satisfaction increases when online medical records and doctors' notes are provided (Delbanco et al., 2010; Delbanco et al., 2012; Fowles et al., 2004; Ralston et al., 2007).

Over the course of 1 year, the OpenNotes study allowed patients in three geographically and clinically diverse health care systems access to their online medical records and primary care doctors' clinic notes. Most patients reported clinically relevant benefits, minimal concerns, and no difficulty in understanding their doctors' notes (Delbanco et al., 2010; Walker et al., 2011). While our early work has been reassuring in noting that the majority of patients do not report being confused by reading their doctors' notes (Delbanco et al., 2012; Walker et al., 2011), the inherent complexity of medicine may limit the ability of an important subset of patients to truly understand and utilize this new access to their full medical records. Only by enhancing patient understanding can we tailor educational efforts and bridge the gap in benefits for these patients at a time when patient portals are undergoing rapid development and transformation. In this article we describe the characteristics and portal utilization of the subset of patients who reported confusion after viewing their doctors' visit notes.

Methods

Online medical records and doctors' notes were made available to patients at three sites: Beth Israel Deaconess Medical Center (Boston, MA), Geisinger Health Systems (Pennsylvania), and Harborview Medical Center (Seattle, WA). Study participants were given access to their primary care providers' clinic notes through an online patient portal for 1 year. Methods have been previously described (Leveille et al., 2012). All sites granted complete electronic access to primary care physician notes to patients for the first time. Study procedures were approved by the institutional review boards of Beth Israel Deaconess Medical Center (BIDMC), Geisinger Health Systems (GHS), and the University of Washington.

Participants completed pre- and post-intervention study surveys that addressed patient demographics, perceived experiences with OpenNotes, and patient–doctor communication. Surveys were in English and not translated. Patients used a 4-point Likert scale to respond to the following postintervention survey question: “The notes were more confusing than helpful.” We collapsed the Likert response categories into a binary outcome of confused versus not confused after reading the note. Patients who selected *agree/somewhat agree* are described as confused by reading their visit note, and patients who responded *disagree/somewhat disagree* are described as not confused by reading their visit note.

Chi-squared tests were performed to determine postintervention differences in characteristics between patients who did and did not report confusion after reading their doctors' visit notes. Multivariate models were developed to evaluate associations between reported health behaviors and perceptions and reported confusion post-intervention. Relative risk (RR) estimates, adjusted for age, education, employment, self-reported health, frequency of portal use, and site, were derived from a modified Poisson regression with

robust error variance. All statistical analyses were conducted using SAS software, version 9.3.

Results

Of the 11,115 patients who completed the 1-year study and had at least one note available during the study, 4,592 patients viewed their available records at least one time and responded to the postintervention survey question regarding confusion after reading their notes. Overall, 3987 (88%) patients reported *disagree*, 399 (8.8%) *somewhat disagree*, 122 (2.7%) patients reported *somewhat agree*, and 20 (0.4%) *agree* to the survey question “The notes were more confusing than helpful.” An additional 64 participants answered *don’t know* and were excluded from the analysis, resulting in the final study sample of 4,528.

Table 1 stratifies demographic characteristics and Web portal utilization by patients who were and were not confused by reading their doctors’ notes. Patients who were 70 years or older reported the most confusion from reading the visit notes (7.0% among patients >70 years of age, compared to 2.0% reported among patients 18–49 years of age). Compared to patients who were not confused by reading their doctors’ notes, patients who reported confusion from the notes had fewer years of education ($p < .0017$), were more likely to be unemployed ($p < .0001$), and had lower levels of self-reported health ($p < .0043$). Among the different study sites, the lowest rates of confusion from the visit notes were reported by patients at Beth Israel Deaconess Medical Center (2%), with the highest at Harborview Medical Center (9.0%).

Most patients at the end of the 1-year OpenNotes intervention reported benefits in their health and health behaviors as a result of reading the doctors’ notes. To evaluate the impact of confusion after reading the doctors’ notes on reported health benefits we performed multivariable analysis adjusting for patient age, education, employment, self-reported health, frequency of portal use, and site (Table 2). Compared to patients who did not report confusion from reading their doctors’ notes, patients reporting confusion were less likely to report the following benefits as a result of reading their doctors’ notes: being prepared for visits (RR 0.31; confidence interval [CI] 0.20, 0.47), feeling in control of their health (RR .42; CI 0.25, 0.71), remembering their care plan better (RR 0.26; CI 0.17, 0.42), and understanding their medical conditions (RR 0.32; CI 0.19, 0.54). Patients who reported being confused by reading their visit notes were also more likely to experience worry (RR 4.83; CI 3.17, 7.36) and to report that it was very/somewhat difficult to understand the doctors’ notes (RR 17.61; CI 12.37, 25.07).

Discussion

In our study, most patients (97%) denied that reading their doctors’ visit notes was more confusing than helpful. While only 3% of our study population reported that they were confused by reading visit notes, this percentage still constitutes a large number of patients if considered on a U.S.-population level. A finding that raises concern is that these patients were less likely to report beneficial health behaviors such as being better prepared for visits, feeling more in control of their health, and understanding their medical conditions as a result

of having access to their doctors' notes. Compared to patients who were not confused by reading their doctors' notes, patients reporting confusion were 17 times more likely to find the notes difficult to understand and nearly 5 times more likely to worry more as a result of reading their doctors' notes. These patients were more likely to be older, less educated, and unemployed or retired, and to have lower levels of self-reported health. Our findings give weight to concerns that a small subset of patients, in particular those with limited health literacy, may not gain the potential benefits of electronic medical records, which many other patients find beneficial.

While electronic access to the full electronic health record holds great promise to improve the health and health care of patients, health literacy varies among patients, and the complexity of clinic visit notes has the potential to confound even the savviest readers. Given the evolving state of health care, facilitating patient access to medical records may be an opportunity for providers to improve how they communicate with patients. For example, in contrast to paper records, electronic medical records are always legible and can be easily viewed online, allowing patients to link to medical information on the Internet (Ross & Lin, 2003). Electronic medical record developers could create patient-friendly formats for medical records documentation, provide easy-to-access definitions of medical terminology (e.g., text boxes that appear when users hover the computer mouse over a word), and develop interface capabilities to enable patients to contact their provider to ask questions about their care plan or health. By improving clarity and facilitating communication between patients and providers, electronic access to doctors' notes could decrease the already small number of patients who report confusion when reading their doctors' notes.

Physicians have long been concerned that giving patients full access to their medical records could cause unnecessary confusion and anxiety in their patients, which could in turn generate increased questions from patients and add to already busy physician workloads (Delbanco et al., 2010; Delbanco et al., 2012; Dhanireddy et al., 2014; Fisher & Britten, 1993; Gilhooly & McGhee, 1991; Ross, 1986; Walker et al., 2011). In the OpenNotes study, at baseline before the intervention, nearly half of the primary care physicians across the study sites reported concern that online access to notes would cause confusion or misunderstandings (Walker et al., 2011). It was therefore reassuring that the patients who were confused by reading their doctors' notes were not statistically significantly more likely to contact their doctors' offices about the notes than patients who were not confused by reading their visit notes. Yet these patients accessed the online portal, just as did other patients who did not report confusion, and were not so disengaged that they never contacted their doctors when they had questions about the note. Patients reporting confusion after reading their doctors' notes were older, in worse health, and more likely to report worry, clearly making them patients who warrant attention.

This is the first study to investigate potential patient confusion caused by reading online doctors' notes. The study strengths include a large, geographically diverse population and a rigorous pre-post intervention design. The study also has several limitations. First, our overall patient population was relatively well educated compared to the general U.S. population. Second, this study did not objectively assess patients' understanding of the notes. Patients' health behaviors and levels of confusion after reading their visit notes were

self-reported, and patients may have been reluctant to admit confusion or difficulty understanding. The reasons for confusion from reading visit notes are unknown; thus, we do not know whether confusion reflected technical problems encountered while viewing notes or confusion about the content of the note. For example, we did not assess cognitive impairment in older patients, which may contribute to confusion more than the online format or note content.

Conclusion

The small fraction of people reporting confusion after reading their doctors' visit notes is reassuring as an increasing number of health systems provide access to full medical records online. These data suggest that it may not require many additional resources to develop systems for identifying patients who are confused and offering assistance with interpretation. Yet because patients who were confused by reading their visit notes reported fewer beneficial health behaviors and may miss the many potential advantages of online medical records, it is critical to bridge the gap in patient-provider communication at a time when patient portals are undergoing rapid development and transformation.

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Table 1.

Characteristics and Portal Utilization of Patients Reporting Confusion After Reading Their Primary Care Provider's Clinic Notes ($N = 4528$).

Patient characteristics	Not confused		Confused		Pearson χ^2, p
	<i>n</i>	%	<i>n</i>	%	
	4386	(97)	142	(3)	
Age (years)					
18–39	585	(98)	12	(2)	<.0001
40–49	839	(98)	16	(2)	
50–59	1427	(97)	44	(3)	
60–69	1102	(97)	36	(3)	
70	433	(93)	34	(7)	
Sex					
Female	2656	(97)	76	(3)	0.0917
Male	1730	(96)	66	(4)	
Race ^a					
White	3446	(97)	109	(3)	0.2511
Non-White	307	(98)	6	(2)	
Education ^a					
High school, GED, or less	600	(95)	31	(5)	0.0017
Some college	882	(96)	33	(4)	
College graduate	775	(98)	15	(2)	
Post college	1560	(98)	37	(2)	
Employed ^a					
No (retired/unable to work)	1129	(95)	56	(5)	<.0001
Yes (employed/self-employed/homemaker)	2578	(98)	56	(2)	
Self-reported health ^a					
Fair/poor	596	(95)	32	(5)	0.0043
Very good/good	3272	(97)	100	(3)	
Excellent	517	(98)	10	(2)	
Number of days portal accessed					
First quartile [1–16 days]	1083	(97)	37	(3)	0.054
Second quartile [17–27 days]	1144	(98)	23	(2)	
Third quartile [28–46 days]	1089	(97)	39	(3)	
Fourth quartile [47 days]	1070	(96)	43	(4)	
Study site					
Harborview	70	(91)	7	(9)	0.0014
GHS	1948	(96)	76	(4)	
BIDMC	2368	(98)	59	(2)	

Note. Patients who responded “Don’t know” ($n = 64$) to the statement regarding level of confusion after reading notes are excluded from analysis. Patients responded to the postintervention survey question “The notes were more confusing than helpful” using a 4-point Likert scale. The Likert

response categories were collapsed into a binary outcome of confused after reading the note (*agree/somewhat agree*) and not confused after reading the note (*disagree/somewhat disagree*).

^aNumber of unknown cases: race $n = 660$; education $n = 595$; employed $n = 709$; self-reported health $n = 1$.

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Table 2.

Association Between Confusion After Reading Primary Care Notes and Health Behaviors and Perceptions ($n = 3819$).

Postsurvey responses	Reported confusion	
	Adjusted RR	95% CI
As a result of reading my doctor's notes: ^a		
I am better prepared for visits	0.31	0.20, 0.47
I feel more in control of my health care	0.42	0.25, 0.71
I remember the plan for care better	0.26	0.17, 0.42
I understand my health and medical conditions better	0.32	0.19, 0.54
I do better with taking my medications as prescribed ^b	0.67	0.43, 1.04
I contacted my doctor's office about something in my notes ^c	1.12	0.57, 2.20
I worry more	4.83	3.17, 7.36
How easy was it to understand your doctor's notes? ^d		
Somewhat/very difficult	17.61	12.37, 25.07

Note. Estimates derived from modified Poisson regression with robust error variance, adjusted for age, education, employment, self reported health, frequency of portal use, and site. The model uses only patients with complete data in Table 1. Patients with missing covariates of race, education, employed, or self-reported health ($n = 709$) are not included in the model.

^aPatients responding *disagree* or *somewhat disagree* to the statement served as the reference.

^bAmong patients who reported taking medications ($n = 3414$).

^cPatients who did not contact their doctor's office served as the reference.

^dPatients responding *very easy* or *somewhat easy* served as the reference.