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Perceived difficulty differences in print and online patient education materials

Michael Arlington Farnsworth
James Madison University

Perceived Difficulty Differences in Print and Online Patient Education Materials

Michael A. Farnsworth

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Table of Contents

Abstract

The empirical study that is the subject of this essay extends work on readability with an explicit focus on whether readers report difficulty understanding health information in print versus on screen. The central concern of this essay, then, is not a matter of reading levels or penetrability of the text, but of how the delivery mechanism interferes with or enhances a person's reading experience through their perception of its difficulty.

Though the study relies on convenience sampling with a limited number of participants, findings suggests that some first-year college students perceive online PEMs to be more difficult to read than print-based ones—even when the reading level of the PEMs is similar. While further study will be needed to confirm the results in randomly sampled populations, demographic information about the sample's high levels of digital literacy suggests that other populations might also perceive online PEMs as more difficult to read than print-based equivalents. Patients' perceptions of the difficulty of patient education materials (PEMs) influence their ability to effectively learn from those materials. This work, thus, concludes with a call for more research into patients' perceptions of difficulty of PEMs in print versus on screen.

Introduction

My brief career as an adjunct instructor of Philosophy sparked an interest in understanding the particulars of how people learn in different formats. I taught Introduction to Philosophy, as well as Practical Reasoning, for Brookdale Community College in Lincroft, New Jersey. After teaching for one year, I sought out an opportunity to develop an online version of Practical Reasoning. At this point, I had taught for one year, or four course sections of Practical Reasoning. I taught the online section of Practical Reasoning for another year, which consisted of three total sections. I have always been somewhat skeptical of online learning courses or programs; however, I held the loose hypothesis that technical subjects—subjects with definitively "correct" answers—would probably fare better in online formats than would more creative, less technical subjects. Explaining why a math problem, say, is incorrect over a format where many aspects of communication are removed seemed much easier than explaining why *War and Peace* is a great book.

Practical Reasoning, I maintained, bridged the gap between technical content and creative, or even subjective, content. The first half of the course dealt with argument forms and fallacies, most of which are clearly identifiable and the application of which left little room for dispute. Conversely, the second half of the course attempted to apply those reasoning skills to many perennial problems in philosophy, which included ethical topics such as euthanasia, metaphysical topics such as the existence of God, and topics from aesthetics, such as the nature of beauty. The topics we examined later in the course, though they relied on the reasoning skills outlined in the first part of the course, were often colored by biases and subjective judgments. Further, many elements of these latter topics were not necessarily identified by the texts and exercises we considered in class or even by human thought in general. Fallacies and argument forms, however, were discussed in a similar fashion in most introductory texts and had been for decades.

Anecdotally, at least, my hypothesis was correct: the first half of the semester seemed relatively similar in both my online and my classroom sections.[1] That is, the degree to which students learned argument forms and fallacies was approximately equal in both course formats. The quality of learning in the second half of the semester, however, degenerated somewhat in my online classes, while my classroom sections did not seem to have any additional difficulties with the applied topics discussed latter in the course. Many of the finer points of the arguments that we were creating and examining were purportedly lost to the vast amount of information and distractions found on the Internet, and perhaps in the students' learning processes themselves. After all, I was providing very similar information in both my online and my classroom courses, so the decreased performance was not due to particulars of the subject matter itself.

A year later, when I enrolled as a student in Professor Michael Klein' Research Methods course, my personal experiences as a teacher helped fuel my interest in researching the discrepancies between online learning and learning in other settings, such as from printed materials or in-person from a teacher. This interest dovetailed with my focus in healthcare communication. Specifically, the potential pitfalls of researching one's own health and well-being from the vast and relatively unchecked information

[1] The classroom section was somewhat better in terms of the work that students generated, probably because I was able to personally lead students through exercises that were troubling. The benefit of extra examples and the many nuances of in-person communication, such as voice inflection and eye contact, probably assisted this process while in the physical classroom. Also, I'm not making any sort of scientifically rigorous claims here, as there are potentially intervening variables (e.g., as a new teacher, my teaching skills could have greatly improved from my first to my second year, thus accounting for the perceived similarity between online and classroom settings).

available online concerned me. I wanted to learn about how to more effectively deliver patient education materials (PEMs) and wondered whether the concerns that I had experienced as a Philosophy teacher, potentially along with many others, had bearing on users' experiences with online health information.

In Professor Klein's course, I measured perceived difficulty for PEMs delivered in both print and online contexts in a sample population of first year college students. Perceived difficulty acts as an indicator of whether a person will engage in an action. If the action is perceived to be too difficult, then there is a low probability that the person will engage in the action. The PEMs that I considered included approximately equivalent content on various student health topics and also scored similarly in terms of reading grade level. In two types of test for perceived difficulty, students reported that online PEMs are more difficult to comprehend than print-based PEMs.

In the following project, I demonstrate how my data is useful for various audiences. In three independent essays, I speak to healthcare communicators, Writing Studies scholars, and writing teachers. Each of the following three chapters examines a related topic through varying, though often overlapping, perspectives.

While at a the 2013 International Conference for Communication in Healthcare, I was fortunate to have the opportunity to discuss my work with Dr. Tom Janisse, the Editor of the *Permanente*, a journal that publishes topics in scientific research, clinical medicine, and health care delivery. Dr. Janisse invited me to submit my work, which is currently in the process of publication at the *Permanente* and is available in the first chapter of this thesis project. In chapter one, I focus on the particulars of my study and draw preliminary conclusions about the study's relevance and about best practice advice for healthcare communicators and teachers of writing that might result from additional research. I expand these latter two preliminary conclusions in chapters two and three.

In chapter two, I use demographic information about the sample population to infer that the sample probably has higher than average levels of digital literacy. I incorporate literature about the “digital divide,” as well as the “digital native/ digital immigrant” distinction, in order to construct my argument. If this inference is conceptually sound, then my conclusions should have bearing on populations with lower levels of digital literacy because such populations would perceive PEMs to be at least as difficult as would those populations with higher than average levels of digital literacy. This is because level of digital literacy is inversely proportional to perception of difficulty.

In chapter three, I use findings from the above study propose suggestions about best practices for online PEM creation and dissemination. I also discuss how considerations of digital literacy can impact writing curriculum development. These recommendations depend on two relevant trends in healthcare: patient-centered care and evidence-based practice.

Chapter 1

Perceived Difficulty Differences in Print and Online Patient Education Materials

Abstract

The empirical study that is the subject of this essay extends work on readability with an explicit focus on whether readers report difficulty understanding health information in print versus on screen. The central concern of this essay, then, is not a matter of reading levels or penetrability of the text, but of how the delivery mechanism interferes with or enhances a person's reading experience through their perception of its difficulty.

Though the study relies on convenience sampling with a limited number of participants, findings suggests that some first-year college students perceive online PEMs to be more difficult to read than print-based ones—even when the reading level of the PEMs is similar. While further study will be needed to confirm the results in randomly sampled populations, demographic information about the sample's high levels of digital literacy suggests that other populations might also perceive online PEMs as more difficult to read than print-based equivalents. Patients' perceptions of the difficulty of patient education materials (PEMs) influence their ability to effectively learn from those materials. This work, thus, concludes with a call for more research into patients' perceptions of difficulty of PEMs in print versus on screen.

Introduction

Effective patient education is a continuing objective in healthcare, and patient education materials (PEMs) provided in both print-based and online formats play important roles in this aim. Written PEMs (both print-based and online) frequently exceed the reading ability of the general public.[1, 2] Perhaps more importantly, though, patients are often intimidated by the task of reading PEMs, perceiving PEMs' difficulty levels as prohibitive, even in cases where the PEMs are not written in excessively technical language and do not exceed the patients' reading abilities.[7]

Research projects that take up patients' *perceptions* of the readability levels of PEMs may help patient educators more effectively create and distribute them. The empirical study that is the subject of this essay extends work on readability with an explicit focus on whether readers report difficulty understanding health information in print versus on screen. The central concern of the this essay, then, is not a matter of reading levels or penetrability of the text, but of how the delivery mechanism interferes with or enhances a person's reading experience through their *perception* of its difficulty. Though the study relies on a convenience sample with a limited population, evidence suggests that participants, first-year college students, report more difficulty reading online PEMs than reading print-based PEMs—even when the reading level of each is consistent.

To date, no published studies have compared levels of perceived difficulty between online and print-based PEMs. Most PEM researchers have focused on readability levels in print media [2] or online media [3, 4] but have not yielded comparative analyses of either print or online formats. The measure of perceived difficulty has received comparatively little attention recently, except by Leroy et al., who launch many promising investigations of perceived difficulty, though not through a comparison of print and online formats. The following discussion of the limitations of readability measures may help demonstrate the promise of using perceived difficulty measures in addition to readability to evaluate PEMs presented in both print-based and online media. While follow-up research will be needed to verify the limited findings presented here, this preliminary study indicates promising directions for future inquiry worth pursuing.

Background

Readability-Based Improvements to PEMs

Historically, creators of PEMs have sought to lower levels of PEM readability, where readability is measured by years of education necessary to comprehend a text. Levels of readability can be determined with a number of formulas, including the Standard Measure of Gobbledygook (SMOG), the Gunning Fog index, and the Flesh-Kincaid Grade-Level formula, each of which is recommended by the Health Literacy Advisor. The SMOG is also recommended by the Centers for Medicare and Medicaid Services. These formulas are useful as basic guides for pairing PEMs with appropriate audiences and for tracking attempts to improve PEMs' content. Understanding readability-related problems helps identify areas of need for alternative approaches to PEMs improvement, such as perceived difficulty measures.

Both print-based and online PEMs are written at reading grade levels that exceed the reading ability of most patients. A recent study of the readability of online health literature found a mean reading grade level of 12.30 from a sample of 352 websites, using the readability tests , SMOG, Gunning FOG and Flesh-Kincaid.[4] A similar study focused on readability of source material for PEMs provided by private electronic health record (EHR) vendors, as well as the National Library of Medicine. The study found that these vendors' PEMs with reading grade levels far greater than the fifth through sixth grade recommendations provided by the European Commission or the Health Literacy Advisor in their code of conduct for the readability of health information.[1] The American Medical Association and the National Institute of Health also recommend that readability levels not exceed the sixth-grade level, while the Center for Disease Control and Prevention recommends that readability levels be at or below the eighth-grade level.[16] These studies demonstrate that many PEMs are largely inaccessible to general audiences.

Complicating the readability landscape, the results of the various available readability formulas often vary greatly. Wang et al. found that readability varies by up to five reading grade levels, depending on which readability test is applied.[2] The SMOG formula has a standard error of approximately one and a half grade levels, where the Flesh-Kincaid has a standard error of up to two and a half grade levels. Effectively, the SMOG varies by up to three grade levels, or twice the standard error, while the Flesch-Kincaid varies up to five grade levels. For this reason, the Journal of the Royal College of Physicians of Edinburgh stated that "SMOG should be the preferred measure of readability when evaluating consumer-orientated healthcare material."[3] These findings demonstrate the complexities involved in applying readability formulas to PEMs. There is, for instance, significant potential for underestimating or overestimating with the use of either formula, but the SMOG produces more accurate approximations.

A related issue that can lead to variation in reported levels of readability is formatting. Often, readability tests fail to incorporate considerations involving overall passage length, individual paragraph length, as well as margin use and other formatting issues; however, these issues may play a significant role in a reader's comprehension of a document. Specifically, readability formulas are often difficult to apply to PEMs written in outline formats; outlines, which often depend mainly on sentence fragments, do not clearly reflect sentence length—a primary factor in readability calculations. In sum, readability tests have entered many domains beyond those for which they were originally created. In these ill-suited contexts, they potentially fail to clearly represent the reading grade level or actual difficulty of health information. However, readability tests justifiably remain a popular tool for evaluating health information, as they can rapidly provide gross approximations for establishing PEMs' difficulty, as measured through an estimation of reading grade level.

Applying Perceived Difficulty Measurements to PEMs

Several conceptual frameworks have been designed to help explain why patients engage in or fail to engage in a variety of health-related behaviors; these measures attempt to account for why some patients are compliant and others are not.[5, 11, 14] These frameworks examine the presence of possible impediments to successful completion of health-related behaviors. One barrier to health-related behavior is "perceived difficulty," which impedes patients from engaging in health-related behaviors due to belief that the difficulty of engaging in such behaviors is prohibitive. Leroy et al. state that "[i]n the context of consumer education, perceived difficulty of the text is a barrier encountered by many consumers who are expected to read text and educate themselves."[6] Both the perceived and actual difficulty of PEMs, then, might act as barriers to patient education by impeding patients from obtaining knowledge about their medical condition.

Levels of perceived difficulty can be altered through manipulations of surface level grammar and term familiarity.[6] Surface level grammar manipulations include changes to sentence structure, noun phrase complexity, and function word density. Sentence structure manipulations include constructing a sentence with either an active voice or a passive voice. Overall sentence structure can also change by writing the sentence with an extraposed subject or a sentential subject. Complex sentences often have sentential subjects, which contain the elements of sentences as subject terms. For example, a sentence with a sentential subject might read "the symptoms that were observed during intake were cough and fever." On the other hand, extraposed subjects use "placeholders," such as "it," for more complex terms or descriptions.

Function words, such as "in," "why," "be," or "the," also effect sentence structure and, in turn, perceived difficulty. Noun phrase complexity increases as the number of function words decreases. Finally, intuitive ease of reading decreases as the number of function words in a sentence decreases. Consequently, a liberal use of function words may lower levels of perceived difficulty. Each of the three methods described above requires time commitments and writer expertise, and thus may prove prohibitive for many attempts to improve PEMs.

Term familiarity is defined by the frequency of a term in the Google web corpus, a database of over a trillion words. The measure of term familiarity helps explain why words with fewer syllables (i.e., more "readable" words) are sometimes more difficult to comprehend.[7] For example, the corpus helps identify why certain shorter words, such as "apnea," are actually more difficult for most readers than words like "obesity." Term familiarity presents a hopeful direction for PEM improvement due to the fact that term familiarity, similar to readability, can be assigned by computational means with the use of algorithms.

The current study adds to this area of inquiry by indicating that the perceived difficulty of PEMs is also a function of presentation media (e.g., online or print). Acting as a hopeful launch for future research trajectories of greater scope, the following research suggests that patients may perceive online PEMs to be more difficult than commensurate print-based PEMs—even when issues addressed above are not a factor.

Methods

The objective of this research project is to determine whether first year college students perceived online or print-based PEMs as more difficult.[2] The study additionally sought to measure the students' perceived difficulty level of each PEM using a Likert type scale.

This study was approved by university Institutional Review Board (IRB Protocol: 13-0141; approved on November 8, 2012). The research was collected at James Madison University (JMU) in Harrisonburg, VA during November 2012 in computer labs with approximately 30 computers per room. The sampling methodology was convenient: participants were from four course sections of GWRTC 103, Critical Reading and Writing. All students voluntarily participated; none refused to participate. Most students

[2] This was a convenience sample. The author had access to this population while in pursuit of a M.A. at James Madison University in the Writing, Rhetoric, and Technical Communication department, where he focused on medical writing, communication, and rhetoric.

take GWRTC 103 during their first year, meaning that they are members of the class of 2015. The class of 2015 at JMU is composed of 4,632 enrolled students, most of whom are members of the Millennial Generation, also referred to as "Generation Y." Despite the fact that this sample was convenient, particular demographic and psychosocial information about the sample may still have important implications for additional populations in future research; this topic will be discussed at length in the "Discussion" section.

Barring specific petition for exemption, all students entering JMU are required to take GWRTC 103, which means that each group of students included a mix of academic majors from across the university. Thus, this sample should be generally representative of University's first year class. Survey data from the JMU Office of Institutional Research shows that 83 percent of the class of 2015 was 21 or younger at the time of the study.[12] Therefore, these students are approximately ten years younger than necessary for inclusion in the "digital native" classification, as stipulated by Prensky.[9] Additionally, 87 percent of the class of 2015 graduated in the top third of their high school class and 65 percent come from a background with an estimated family income of 100,000 dollars or more annually.[12]

Forty-one students participated in the research. Each student received PEMs about two of four possible topics familiar in student health contexts. In effect, data were collected about 81 pairs of PEMs, n = 81. The topics included: conjunctivitis ("pink eye"); mononucleosis ("mono"); self-care for cuts, scrapes and burns; and back exercises. Topics were paired in all possible combinations, resulting in six survey forms, A through F. The survey forms were:

A: Pink Eye and Mono
B: Pink Eye and Cuts, Scrapes and Burns
C: Pink Eye and Back Exercises
D: Mono and Cuts, Scrapes and Burns
E: Mono and Back Exercises
F: Cuts, Scrapes and Burns and Back Exercises

Survey forms were evenly distributed across participants. Each topic was presented in both online and print-based formats. Participants received four total readings: two print readings and two online readings. For example, a student in survey group C received a print PEM on Pink Eye, an online PEM on Pink Eye, a print PEM on Back Exercises, and an online PEM on Back Exercises. All PEMs were used in actual practice, available either at a health center or a health education website. The online readings were selected from popular search results from Google.com; each selection occurred on the first page of Google search results. These PEMs were available at webpages that the students accessed directly.[3] The print-based readings were physical copies provided by the JMU Student Health Center.[4] The SMOG test was used to construct an approximate reading grade level difficulty equivalence between each set of PEMs (e.g., the online and print Back Exercises PEMs). Materials in each set varied

[3] Online PEMs included: Conjunctivitis/Pink Eye: http://www.nlm.nih.gov/medlineplus/pinkeye.html (from the National Institute of Health); Cuts, Scrapes, and Burns: http://www.fairview.org/healthlibrary/Article/84649 (from Fairview Health Services); Back Exercises: http://www.mayoclinic.com/health/back-pain/LB00001_D (from the Mayo Clinic); Mononucleosis/Mono: http://www.webmd.com/a-to-z-guides/infectious-mononucleosis-topic-overview (from WebMd)

[4] Print-based PEMs included: Conjunctivitis/Pink Eye: “Conjunctivitis (“Pink Eye”)” (from University Health Center); Cuts, Scrapes, and Burns: “Self-Care for Cuts, Scrapes and Burns” (from Quality Health Care); Back Exercises: “Back Exercises” (from Parlay International); Mononucleosis/Mono:

“So You Have Mono” (from the American College Health Association) approximately two reading grade levels. Please see Tables 1 and 2 for examples of the WebMD and American College Health Association text.

Note that the online text from WebMD was 2.3 grade levels lower than the printed brochure according to the SMOG and 1.4 grades lower according to the Flesch-Kincaid measurement; based on the expected standard error for these readability measures (the SMOG formula has a standard error of approximately one and a half grade levels, where the Flesh-Kincaid has a standard error of up to two and a half grade levels), this sort of variation means that the texts may actually be almost identical reading grade levels or may vary by up to approximately 3.8 grade levels according to the SMOG and approximately 3.9 grade levels according to the Flesch-Kincaid. The WebMD example scored 4.7 for the SMOG and 5.4 for the Flesch-Kincaid, while the American College Health Association brochure scored 7.0 for the SMOG and 6.8 for the Flesch-Kincaid.

The survey was available for the participants at the same time they viewed the patient education materials, so that they could refer back to the readings for confirmation of their assigned levels of difficulty. All surveys were collected in Qualtrics. The survey questions asked the students to provide two kinds of difficulty rankings of the patient education materials.

The first question asked the participant to decide whether the online or print-based education material was more difficult concerning the same subject matter (e.g., the subject matter, “pink eye”). This question requested an ordinal ranking from the student. An example of this kind of question follows: “Which was easier to read: the online material on conjunctivitis (“pink eye”) or the paper material on conjunctivitis?” Three additional questions resulted from the other three subject matters in the respective PEMs.

The results for each subject matter (e.g., mono, pink eye, back exercises, etc.) were combined in order to find an overall ranking for print PEMs and an overall ranking for online PEMs. The generalized, two tailed hypothesis stated that the format (online or print) would produce a statistically significant difference in the resulting rankings.

The second survey question asked the participant to rank the difficulty of each type of PEM, online and print-based, for both subject matters. These cardinal difficulty rankings were recorded on a seven-valued Likert Scale from “very difficult” to “very easy.” Similar to the first question, in this case, the generalized, two-tailed hypothesis stated that students would report significantly different rankings for online versus print-based PEMs.

Results

The first hypothesis was analyzed with a Chi-squared test, while the second hypothesis was analyzed with a T-Test. The first hypothesis did not reflect a statistically significant difference, while the second hypothesis did reflect a statistically significant finding. The statistical tests were computed in the statistics program, IBM SPSS Statistics.

Overall, participants ranked the print-based PEMs as less difficult than online PEMs in a test of hypothesis one. Across 80 difficulty rankings, participants ranked print-based materials as less difficult in 43 cases and more difficult in 37 cases, which did not reflect a statistically significant finding, $p = 0.45$. Please see Table 3 at the end of the document.

In the second hypothesis, participants reported an average ranking of 6.03, or "Somewhat Easy," for the online PEMs, while they reported an average ranking of 5.48, or"Easy," for the print PEMs, which reflected a significantly significant difference, p = .000015. In the Likert scale, "Very Easy" translated to a value of 7, "Easy" to a value of 6, etc. Please see Table 4 at the end of the document.

Discussion

Limitations

Sample Population

This study dealt with a limited population: first year students at James Madison University. The sample size was also small. Further, larger scale studies of perceived difficulty rankings of PEMs amongst additional demographics or in more randomized settings will help to produce more generalizable information about the differences between print-based and online PEMs. This study offers starting points and directions for future research and does not provide immediately generalizable knowledge.

Variation between Health Topics

The current study groups four popular student health topics together, though there may be important differences between topics (e.g., the online or print format may have led to a larger divide in reported perceived difficulty concerning an individual topic than is reflected by the pooled information, which was analyzed in this study). Further, student health topics, such as those examined here, may not be representative of other sorts of PEMs. Subsequent work may wish to examine a wide range of health topics individually and with relevant populations to better understand, in each case, whether patient perception of difficulty is influenced by presentation media.

For instance, it may be argued that since mononucleosis has a strong association with promiscuity—a potentially charged topic—thus, health information seekers may experience additional difficulties when learning about this topic. Conversely, a topic that does not invoke similar emotional responses, such as back exercises designed to help stave off back pain, may not include similar impediments to learning.

Conclusion

This research presents a starting point for future research on the influence of delivery media on the perceived difficulty of PEMs; larger scale studies with more randomized samples may more conclusively demonstrate that online PEMs are more difficult to comprehend. What this study offers, then, is an indication of the topic's importance and a model for a relatively easy to follow protocol. That is, other researchers might select randomized samples from relevant populations, choose PEMs for examination that cover topics relevant to the studied population, and use Qualtrics or other survey software to compile and analyze valuable information about the examined PEMs. As well, clinicians could conduct their own small-scale inquires like my own in order to learn more about the dispositions toward PEMs in variant mediums. Findings outlined above concluded that first year students at JMU perceive print-based PEMs as less difficult than online PEMs. The students reports that online PEMs were more difficult to comprehend may be further supported by the observation that the online

PEMs were written at higher reading grade levels, as demonstrated in the SMOG and Flesch-Kincaid measurements above.

If one agrees that these students likely have higher than average levels of digital literacy, then it is not a stretch to hypothesize that other populations who have demonstrably lower levels of digital literacy may also perceive online PEMs to be more difficult than print-based PEMs. The discussion below argues that these students probably do have higher than average levels of digital literacy. This claim presents reasons for further inquiry into perceived difficulty differences between print and online PEMs amongst other populations, perhaps while tentatively maintaining the hypothesis that most user groups will perceive online PEMs to be more difficult than print-based PEMs.

Growing consensus suggest that there is a positive correlation between digital literacy and a number of demographic and psychosocial factors, which include: being born in the early 1980s or later; having at least middle-class socioeconomic status; and having high levels of general literacy.[9,10, 13] As discussed in the "Methods" section above, these students were in fact born later than the 1980s, have at least middle-class socioeconomic status (indicated by household income), and have high general levels of literacy (indicated by their class standing in high school). These students' characteristics present reasons for believing that they have higher than average levels of digital literacy. Regardless of whether or not readers agree with the assessment of digital native status above, future study might manage to confirm that most populations perceive online PEMs as more difficult. Health educators may, then, wish to direct patients towards print-based PEMs before they consult online PEMs and might approach online PEMs with caution despite the growing availability of these PEMs.

Moreover, as healthcare systems move towards a preventative focus and patient-centered care, patient education may receive increased attention; thus, the effectiveness of PEMs delivery may become an increasingly pressing concern. Though knowledge *that* delivery media affects delivery is important, knowledge of *how* the delivery media affects patient understanding may also help patient educators better create and distribute PEMs. In particular, investigators might attempt to understand why online PEMs are perceived as more difficult.

Although precisely why online PEMs might be perceived as more difficult is beyond the scope of the current project, potentially fruitful directions for hypothesizing to that end might include distraction in online environments, the cognitive difficulties associated with reading on a screen, and the processes associated with searching for and opening webpages.

At first glance, a number of factors may add to difficulties associated with understanding PEMs in online contexts. These factors may include increased distraction in online environments from advertisements or other applications; cognitive difficulties associated with reading on a backlit screen; and the processes associated with searching for and opening webpages. Additionally, a content analysis of current online PEMs' use of web-writing and web-design best practices may highlight important differences between writing designed for online and print-based contexts. These and other possible factors deserve attention to better understand why online PEMs are perceived as more difficult, should that tentative conclusion receive further confirmation.

Tables:

Table 1
Example text from WebMD (http://www.webmd.com/a-to-z-guides/infectious-mononucleosis-topic-overview)
How is it treated? Usually only self-care is needed for mono. Get plenty of rest. You may need bed rest, which could keep you away from school or work for a little while. Gargle with salt water or use throat lozenges to soothe your sore throat. Take acetaminophen (such as Tylenol) or ibuprofen (such as Advil) to reduce fever and relieve a sore throat and headaches. Never give aspirin to someone younger than age 20 years, because it can cause Reyes syndrome. Avoid contact sports and heavy lifting. Your spleen may be enlarged, and impact or straining could cause it to burst.

Table 2
Example Brochure from the American College Health Association, “So, You Have Mono: Taking the Next Step”
How Mono is treated. There is no specific treatment for mononucleosis. In order to get better as quickly as possible, you need to take care of yourself so your immune system can fight the infection. Antibiotics are not useful in treating viral diseases such as mono. You will need to get plenty of rest (8 to 10 hours of sleep a night). Medications such as ibuprofin or naproxen are helpful for your fever, sore throat and other aches and pains. DO not use aspirin if you are 18 years old or younger because of the risk of reyes syndrome. It is important to drink plenty of liquids, even though you may not have a good appetite. Soup broth, sports drinks and rehydration fluids supply these nutrients. Popsicles, sodas and flavored ices as well as just water are also excellent ways to stay hydrated.

Table 3: Chi-Square Test			
Frequencies 1="print" 0= "online"			
	Observed N – Perceived as More Difficult	Expected N	Residual
Online	43	40	-3
Print	37	40	3
Test Statistics			
1="print" 0= "online"			
Chi-Square	.450a		
Df	1		
Asymp. Sig.	0.502		

Table 4: T-Test					
Paired Samples Statistics					
		Mean	N	Std. Dev.	Std. Error Mean
Pair 1	Print	6.037	81	1.1005	0.12228
	Online	5.4815	81	1.37032	0.15226

Paired Samples Test

		Paired Differences					T	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	Print – Online	0.55556	1.08397	0.12044	0.31587	0.79524	4.61	80	0.000015

Chapter 2

1. Introduction

In recent years, scholars in Writing Studies have wondered whether generational affiliation is an accurate indicator of one’s comfort level with reading and writing in electronic environments. Specifically, discussions have centered on whether today’s traditional-age college students have higher than average levels of digital literacy due to their familiarity with technology throughout preadolescence, adolescence, and early adulthood, thus qualifying them as “digital natives.” Accepting the premise that today’s college students are, in fact, digital natives means also accepting the premise that the vast majority of their instructors are by and large “digital immigrants” who learned to use digital technologies after early adulthood. In this essay, I use data from my study that measured the perceived difficulty of reading patient education materials (PEMs) across online versus print formats, which was conducted on first-year college students, to suggest that many “digital immigrant” populations may perceive online PEMs to be more difficult than print-based PEMs.

My study, which was conducted as part of my Writing and Rhetoric graduate coursework in research methods, relied on a convenience sample: the student population. The main goal of that research was to determine students’ perceptions of difficulty reading online versus print patient education materials (PEMs), but my data seems, also, to add valuable insight into ongoing conversations of digital native versus digital immigrant status—especially in contexts where writing is taught. Additional populations, of course, would need to be studied in order for me to posit much more than a preliminary conceptual argument. That is, I want to emphasize here that these students' digital literacy levels were not directly measured, so the conclusions reached in this essay are presented with some reservation and are offered in the spirit of joining ongoing conversations. A future study that directly measures digital literacy levels would present firmer conclusions in a social scientific sense. Even with these limits in mind, those interested in digital literacies in college student writers might find my data compelling nonetheless.

In the following conceptual argument, I use demographic information about the sample population to infer that the sample *probably* has higher than average levels of digital literacy. In a sample population of first year college students, I measured perceived difficulty for PEMs delivered in both print and online contexts. Students reported that online PEMs are more difficult to comprehend than print-based PEMs. When I initially analyzed my findings, I used Information about the sample population, namely, their status as "digital natives," to infer that the study's findings may apply to additional populations who qualify as "digital immigrants."

In this essay, I focus on whether the sample of first year college students (born between 1996 and 2000) possess higher than average levels of digital literacy. As my discussion progresses, the term "digital native" functions more as a place-holder for "someone who is digitally literate" than as a meaningful distinction. In point of fact, the inference turns on whether the student population has a high level of digital literacy, rather than whether they are digital natives. After arguing that the students probably do have higher than average levels of digital literacy, I use information from my study to generalize about other populations' interactions with print-based and online materials.

In order to make this argument, I examine the origin and importance of the distinction between digital natives and digital immigrants and discuss how that distinction can help show that the study's results may apply to additional populations and analogous contexts. I also point toward some challenges to the digital native/digital immigrant distinction that threaten its status as a meaningful distinction, further emphasizing that a more meaningful distinction should function directly on digital literacy. I offer, too, a limited, contextually dependent defense of the so-called digital native/digital immigrant distinction and discuss how this distinction allows for an inference from information collected my study to additional populations. These implications, I conclude, are useful for writing teachers and healthcare communicators to consider.

2. The digital divide and related inferences

The digital native concept originates in Marc Prensky's (2001) article, "Digital Natives, Digital Immigrants Part 1," where he claimed that students with birthdates beginning around 1980 or later have high levels of digital fluency due to their lifelong immersion in digital technologies. Prensky introduced the term, "digital native," to describe members of this population. In contrast, older, "digital immigrant" populations learned this "digital language" later in life when brains are not as receptive towards language learning (Prensky, 2001, p. 3). Prensky relied on the concept of neuroplasticity, which is the idea that behavioral and environmental changes can lead to cellular changes in the brain. In this sense, exposure to digital technologies early in life—when the brain is most plastic, or adaptable—can lead to high levels of digital fluency.

Similarly, Hayles (2012) supported the neuroplasticity thesis, but claims that the brain can also adapt to technological stimulus later in life: “These environmental changes have significant neurological consequences, many of which are now becoming evident in young people and to a lesser degree in almost everyone who interacts with digital media on a regular basis” (Hayles, 2012, p. 11). Similar to language learning, skills associated with the efficient use of digital technologies are best acquired early in life. For Prensky, being a certain age is both necessary and sufficient for being a digital native, and consequently, for having higher than average levels of digital fluency.

However, it seems uncontestable that despite one’s age, attaining the appropriate hardware, software, and access is necessary for being digitally literate; many discussions about access refer specifically to a “digital divide” between persons with access to digital technologies who are able to become digitally literate and those without access who do not have the opportunity to attain literacy in digital environments. Vie (2008) noted that the digital divide has been called a problem of access (p. 10). Having access to digital technologies is generally correlated with a certain amount of affluence, or the psychosocial variable, “socioeconomic class.” Digital divide studies have repeatedly found that that upper- and middle-class families generally own up-to-date computers and participate in online services (Selber, 2004, p.108).

Oblinger and Oblinger (2005) claimed that in addition to household income, parental level of education could be used to predict levels of digital access and consequently, digital literacy.

> For children whose parents have a high school education or less, 68 percent have Internet access at home. This contrasts with 82 percent for those whose parents

> completed college. The distribution based on median family income is similar: 84 percent of families with incomes over $50,000 have Internet access at home; for those making less than $35,000, the percentage is 66. (Oblinger & Oblinger, 2005, p. 2)

Further, Hawisher, Selfe, and Moraski (2004) suggested that attaining technological literacy often depends on access in a more robust sense. Access through multiple gateways, or devices, in various environments, such as school, the workplace, the community and home, is positively associated with high levels of digital literacy (Hawisher, Selfe, & Moraski, 2004, p. 677).

Additional criteria may also contribute to digital literacy, thus complicating positions that claim that age or access act as primary determinants for digital literacy. Vie claimed that though access is a necessary precondition for digital literacy, “attention also needs to be paid to students’ critical digital literacies,” arguing that technology must be incorporated in classrooms in ways that support students’ other composition-related activities, rather than focusing solely on their ability to operate technological devices (Vie 10). Digital literacy, then, involves the application of critical and creative thinking to other disciplines or genres through the use of digital technologies.

Selber supported the idea that students must be versed in functional, critical, and rhetorical literacy in order to gain digital literacy. For Selber, functional literacy referred to computers as tools and students as users of those tools. Thus, a central component of digital literacy involves learning processes that are necessary for using digital tools (e.g., saving a document to a cloud storage device). But for Selber, as for Vie, digital literacy extended beyond mere functional literacy, or competency in digital tool use.

In contrast, critical literacy engages questions that consider why and how various digital technologies have been popularized in order to shape the cultural and political climate. Critical literacy encourages reflection about technologies as artifacts of social and political use. For example, critical reflection might help demonstrate that an informational website was created with the clandestine interests of persuading members of a particular population to vote for a specific candidate.

Finally, through rhetorical literacy, Selber encouraged students and faculty to evaluate the ways in which digital technologies could have been designed in alternate ways to reshape the current cultural and political climate. For instance, an informational website such as that mentioned above might instead discuss political issues in a more objective, nonpartisan fashion. To realize such transparent display of information, related legislation might require contributing political parties to clearly identify themselves, thus alerting users to potential biases. Selber claimed that each component of literacy is necessary for digital literacy in a significant sense. "Students who are not adequately exposed to all three literacy categories will find it difficult to participate fully and meaningfully in technological activities" (Selber, 2004, p. 24).

Unifying the work of the authors discussed above yields a set of criteria associated with increased levels of digital literacy, which further help refine the concept, “digital native.” As mentioned above, the more relevant issue concerns the identification of traits positively associated with high levels of digital literacy, rather than the specific delineation of a “digital native” population. The criteria are: being born around 1980 or later; having a background that fosters functional, critical, and rhetorical literacy; and having upper- or middle-class socioeconomic status. While no single criterion listed above is sufficient for making a person a digital native, it seems reasonable to assume that *most* members of a demographic group that have a high incidence of these traits can be called digital natives in the sense that they *probably* have high levels of digital literacy.

3. Challenges for the digital native/digital immigrant distinction

The terms "digital native" and "digital immigrant" have been met with controversy since shortly after their introduction in Prensky's article. The terms have been contested both on the grounds of their utility and of their empirical accuracy.

Brown summarizes a central concern related to the effects, or utility, of using the terms, "digital native" and "digital immigrant." Below, Brown suggests that the terms are exclusionary and may convince persons who do not fit the digital native profile that they have inherently low aptitude for learning in digital environments:

> A serious problem with the idea of the 'digital native' is that it is an 'othering' concept. It sets up a binary opposition between those who are 'natives' and those who are not, the so-called 'digital immigrants'. This polarization makes the concept less flexible and more determinist in that it implies that if a person falls into one category, they cannot exhibit characteristics of the other category (Brown, 2010, p.357).

In this sense, aside from any considerations of its descriptive accuracy, use of the "digital native" concept has normative implications. Extensive use of these distinctions may cause persons born before the early 1980s to decide *a priori* that they will be unable to attain skill in using various digital technologies. Clearly, most applications of digital technologies (e.g., sending emails, performing online searches, and engaging in social media) can be learned to at least some level of proficiency by most potential users. The idea that simply belonging to the digital immigrant population leads to a diminished ability for learning digital technologies may act as a barrier for some users to attempt to learn a skill requiring digital literacy. Oblinger and Oblinger used the alternate, and potentially less prejudicial, term, “Net Generation” to refer to the population who has grown up with digital technologies (Oblinger & Oblinger, 2005). Use of this latter term, however, may also have undesirable “othering” consequences because it too relies on an age-based criterion for inclusion in a digitally literate class.

Vaidhyanathan (2008) assumed an even stronger stance by highlighting the idea that use of classifying terms, such as “digital native,” often overshadows other important social inequities that must be addressed by other means entirely.

> Talk of a "digital generation" or people who are "born digital" willfully ignores the vast range of skills, knowledge, and experience of many segments of society. It ignores the needs and perspectives of those young people who are not socially or financially privileged. It presumes a level playing field and equal access to time, knowledge, skills, and technologies. The ethnic, national, gender, and class biases of any sort of generation talk are troubling. (p. 2)

In addition to the undesirable consequences that may result from popularizing the “digital native” concept, these terms may also fail to accurately describe certain older populations. The polarization, or binary, created through use of the terms, “digital native” and “digital immigrant” does not account for persons born before the early 1980s who develop high levels of digital literacy. Thus, the terms “digital native” and “digital immigrant” may present overly narrow—and sometimes misleading—criteria for being digitally literate.

The distinction between “natives” and “immigrants” may have led some researchers to incorrectly observe the digital literacy habits of various demographics. For example, Bowen (2011) discussed ageism biases in data collection in studies such as the Pew Internet and American Life Project. The Pew Project privileges the activities that young people commonly participate in online, while claiming that the activities common among older generations, such as emailing and looking at family photos are basic and “Web 1.0” (Bowen, 2011, p. 588).

Activities such as those mentioned by Bowen surely count as a contributing to a user’s level of digital literacy since these activities require the user to perform skilled, information-processing tasks that require the use of digital technologies and the application of literacy in more traditional senses. Researchers should be careful to avoid ageism biases in their research; popularization of the “digital native” concept has led to some of this bias, producing inaccurate representations of older populations’ online activity.

Despite concerns over the traditional age-based criterion for being a digital native (e.g., being born in the early 1980s), some authors have offered a limited defense of the criterion. For instance, Oblinger and Oblinger (2005) claimed that either age or experience can classify a person as a member of the digital native class. Either factor—age or experience—can contribute to digital literacy and related inclusion in the digital native population. Other studies demonstrate that age alone cannot function as a sufficient condition for being a digital native. For example, Adkins (2011) studied the "undigital" Amish, a population without significant digital access in any age group. Due to limited digital access, even Amish born during or after the early 1980s cannot meaningfully be called digital natives.

As discussed above, Bowen (2011) contended that motivation—and resultantly, experience—toward digital technologies can be detrimentally affected by the use of the terms, "digital native" and "digital immigrant." Relevantly, Bowen attacked the terms on both grounds of their descriptive accuracy and on the grounds that they lead to undesirable consequences.

> If some elders feel inadequate as learners because they have been moved by pervasive public messages that digital literacy is something only young people do, such feelings can impact powerfully their motivation to pursue literate practices with digital technologies. (p. 589)

In a concrete realization of Bowen's concerns, Crow (2006) discussed the complex mix of motivational factors that may assist or hinder aging faculty who attempt to learn digital technologies for classroom use. Incorporating new digital tools can require faculty to adopt a new orientation, which may lead to feelings of pressure to perform and relatedly, ineffectiveness in using the new technologies. Crow suggested instead that new technologies should be introduced in a way that emphasizes a "curiosity-driven" approach that builds on, rather than upends, previously held worldviews (p. 60).

Similarly, models of motivation that focus on positive, rather than negative, incentives may help members of all age groups learn digital technologies. These incentives often convince users to gain more experience with a digital technology, thus increasing their levels of fluency. For instance, a smart phone user who wishes to be able to more efficiently use a Global Positioning System application will often invest time in learning about how the application works and attempting to use it in situations where they need to obtain directions to a particular location.

In a descriptive study that sidesteps ageism concerns by including both “Web 1.0” and “Web 2.0” tasks as examples of activities that require digitally literacy, Bullen reported evidence contrary to the age-based digital native/ digital immigrant divide. Bullen reported no significant differences between the digital habits of various age groups. “[W]e did not find any evidence to support claims that digital literacy, connectedness, a need for immediacy, and a preference for experiential learning were characteristics of a particular generation of learners. (Bullen, 2011, p. 18)

Notably, however, Bullen’s study took place at a public technical and trades training institute in Western Canada that was composed of mostly part-time students, 61 percent of whom were in the 25 – 44 year old age group. Demographic information, such as socioeconomic status, as well as other information about the students’ literacy levels, was not available; thus, the impact of these factors on student literacy levels is unknown. More representative investigations of digital literacy should take into account socioeconomic status and levels of general literacy in addition to age. The following section discusses how many of the factors outlined in this section can be used to repurpose information from the study of James Madison University students for use with additional populations.

4. Demonstration of the digital literacy of sample student population

The selection of literature presented in the prior two sections suggests a gulf in opinion about what demographic and psychosocial factors contribute to levels of digital literacy. However, many researchers after Prensky agree in calling for a more fine-grained distinction than can be garnered through birthdate alone.

Counterexamples based on observation of various user groups demonstrate that younger generations in certain cultural contexts do not have high levels of digital literacy, and thus, that a specific age range is not necessary for attaining high levels of digital literacy. As discussed above, even younger generations who are also members of various religious groups that restrict technology use or from socioeconomically limited populations often have limited digital access and subsequently, have limited digital literacy. Conversely, research that observed populations with more affluent socioeconomic status and higher levels of general literacy shows that these factors contribute positively to levels of digital literacy. And further, although age cannot act as a sole determinant of digital literacy, Prensky’s original message is still important: being born in the early 1980s or later means that there is a greater likelihood of exposure to digital technologies, which can in turn increase levels of digital literacy. To the extent that access to digital technologies has a cumulative effect dependent on the amount of time with access, age functions as access across lifespan development. Thus, those with access from an earlier age can be thought to have higher levels of access to digital technologies.

This essay argues that each of these factors may play an important role in determining a population’s general level of digital literacy, and thus may be used predictively when trying to determine digital literacy levels. However, no factor discussed above is necessary for having a high level of digital literacy, but some combination of the factors is probably sufficient.[5]

The factors discussed above—perhaps along with other factors yet to be discovered—may be described as *inus* conditions (Mackie, 1966). ”This sort of condition, an *insufficient* but *necessary* part of an *unnecessary* but *sufficient* condition, I call for short (using the initial letters of these words) an *inus* condition” (Mackie, 1966, p. 445).

In this sense, it is not necessary that a person be of a certain age range, from a certain socioeconomic background, or have a certain degree of general literacy in order to have a high degree of general literacy. Neither is it the case that a person could satisfy only one criterion and be digitally literate; but some combination of these factors often leads to digital literacy. The *inus* condition seems to apply, since each criterion (e.g., being born after 1980 *or* having at least middle class socioeconomic status) alone is *insufficient* for being a digital native, yet multiple criteria considered jointly may be *sufficient* for being a digital native. Furthermore, the combined criteria in such a case is not *necessary*, but only represents one possible way in which a person may become digitally literate.

If it can be demonstrated with reasonable probability that most James Madison University students from the class of 2015 who were enrolled in GWRTC 103 have some combination of the above factors, then those students *probably* exhibit high levels of digital literacy. The discussion below examines specific demographic information about

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[5] The exception here may be access to digital technologies, which itself may in fact be gained in a number of ways, and thus is not dependent on socioeconomic background alone. Additional studies might examine the variety of ways in which access may be gained (e.g., in schools, in libraries, in the home, etc.). Access is arguably a necessary condition of digital literacy because without access, a person or group cannot reasonably be referred to as digitally literate.

the class of 2015. The specific criteria are: being born in the early 1980s or later; having at least middle-class socioeconomic status; and having high levels of general literacy.

The following data sets, compiled from the James Madison University (JMU) Office of Institutional Research, demonstrate the presence of each of these factors about population of JMU students, and in turn, about the student sample from Critical Reading and Writing. Critical Reading and Writing, GWRTC 103, is an undergraduate level general education course. Barring specific petition for exemption, all students entering James Madison University are required to take GWRTC 103, which means that students from the course are representative of the University population. Most students take GWRTC 103 during their first year making the study sample mainly from members of the class of 2015.

Survey data shows that 83 percent of the class of 2015 was 21 or younger at the time of the study (James Madison University, 2012). This means that most of these students are approximately ten years younger than necessary for inclusion in the "digital native" classification, as stipulated by Prensky and others.

Literacy levels for James Madison University students are generally above average. This claim is evident in their prior performance in high school. Fifty percent of JMU students were in the top quarter of their graduating class. Eight-seven percent of JMU students ranked in the top third of their graduating high school class. Ninety-nine percent of students were in the upper half of high school graduating class. Seventy-four percent of students had SAT scores of 1100 (66 percentile) or higher (James Madison University, 2012).

Information about JMU students' backgrounds may help demonstrate that these students probably had digital access prior to enrollment at JMU. Socioeconomic background and parents' level of education have a positive relationship to digital access (Oblinger & Oblinger, 2005, p. 2). James Madison University students generally come from middle-class socioeconomic households. Sixty-five percent of JMU students come from a background with an estimated annual family income of $100,000 or higher (James Madison University, 2012). A typical middle-class, dual-earner family in the United States has a combined annual income of $97,000 (Beeghley, 1996). Seventy percent of fathers of JMU students had attained a bachelor's degree or higher level of education, while 67 percent of mothers had attained a bachelor's degree or higher (James Madison University, 2012). Since the class of 2015 generally came from middle-class socioeconomic backgrounds *and* came from households where one or both parents had often attained a college education, these students *probably* had digital access while living with their parents or guardians.

Based on the arguments presented above, it seems reasonable to conclude that this population should have higher than average levels of digital literacy. To state the claim more conservatively, no available evidence suggests that the examined population would have *lower* than average levels of digital literacy; thus, the data obtained about this population should be generally applicable to most of the United States population. Application to other specific populations could be further confirmed through evaluation of the extent to which those populations share the demographic and psychosocial factors discussed above.

5. Other considerations and implications for teachers of writing and healthcare communicators

Federal, state, and private investment in digital learning incentives for primary and secondary schools has been extensive. Programs include the Clinton Administration's "Technology Literacy Challenge," the Bush Administration's "No Child Left Behind Act," Congress' proposed "National Digital Literacy Day," California's "Information and Communication Technologies Digital Literacy Incentive," the National Writing Project's Digital Learning Programs, the MacArthur Foundation's digital media and learning initiative, along with myriad others.

Colleges and universities are also highly invested in digital learning. Many Composition and Writing Studies departments have writing centers that offer fully online, offsite assistance in the form of web-based style guides and tutorials, as well as individual tutoring or editing services.

Both public and private healthcare providers have followed suit, investing widely in online patient education and infrastructure to support patient access to electronic medical records (EMRs). Although all these programs have significant benefits, the results of the study outlined in essay one suggest that even learners with high levels of digital literacy can struggle with online material in ways that may be avoided in offline settings, which emphasize the use of printed materials. Of course, the results of my study should not be used to found a Luddite-inspired opposition to technologically supported learning, but rather should caution content developers in hastily placing all content and support online. In fact, further examination of context on a case-by-case basis may help developers better understand when an online medium is appropriate. User perception of credibility varies widely through both the type of media (e.g., television, newspaper, website) and subject matter (e.g., tutorial services, health information, shopping) (Flanagin & Metzger, 2000). Evaluation of credibility may often act as an additional step in the evaluation of online content; user evaluation of health information in particular may prove particularly onerous. This added step in some online contexts may contribute a further barrier to patients engaging in positive health-related behavior.

Eysenbach (2007) explored some of these differences in credibility. While many people develop online usage patterns for topics such as news, weather, and movies, other topics—including health and medical questions—do not occur frequently enough for users to find trusted information sources. Thus, many people may feel competent to evaluate the quality of information for a general news website, but not a health information website (Eysenbach, 2007, p. 124).

A Pew Internet and American Life Project (2000) study confirmed that online health information seekers are particularly wary of obtaining health information online. "86% of health seekers users are concerned about getting health information from an unreliable source online" (Fox, 2000, p.6). In order to avoid this possibility, 30 percent cross-checked the information they obtained across at least four websites and 58 percent looked to see who authored the information they obtained (Fox, 2000). This behavior suggests that many users add an extra step or steps to their health information-gathering activities when looking for information online. Notably, my study operated in a controlled, "push" model of information dissemination where students did not need to gather, verify, or cross-reference the health information they read. Students were given links to specific websites, which they compared to printed materials with similar readability levels. At a health center, patients have already entrusted many of their healthcare decisions and practices to the employees at that health center. Transitively, those patients would probably also trust the health information provided directly at the health center, such as brochures, other printed materials, and perhaps also a website directly sponsored by the health center. Thus, the activities of verification and cross-referencing play a smaller role with health information obtained directly from health centers.

In contrast, online health information seekers operate on "pull" models, where consumer need dictates information-gathering strategy. Users must use search engines to find information. This additional complication to health information seeking online suggests that there may be even larger discrepancies in perceived difficulty between print and online contexts than my study suggests.

The particular health information sought may also lead to attitudes and actions admitting of varying degrees of conservatism. This range of attitudes and actions are largely dependent on the health concern's perceived seriousness and perceived threat to the patient. For example,

> "[A] teenager said, 'I wanted to know how to get rid of a wart on my toe without the doctor—so I looked on the Internet and it told me stuff like how to get rid of plantar warts.' At the same time, many consumers recognize the limitations of self-care and will be more wary to bypass health professionals if they have a more serious disease. For example, in the same study, another teenager said, 'You're not going to go on the Internet if you have cancer… if you've got a big tumor or something.' (Eysenbach, 2007, p. 125)

Additionally, embarrassment concerning sensitive health topics or the need to find an immediate solution to a health concern may cause users to find information on the Internet, rather than by consulting a medical professional. In these sorts of cases, the user often lowers their standards for information quality or perception of credibility. This diminished requirement for information quality may cause injurious results from users accepting the advice of poor sources or applying the information out of context (Eysenback, 2007).

User ascription of credibility is often further muddled by the confusion of PEMs with advertisements and failure to properly identify authoritative sources. Aside from user perception of credibility, the “actual” credibility of online health information is often highly variable. The ease of online publishing and lack of quality control are cause for serious skepticism of the quality of information content. Further, even accurate health information that is misinterpreted or used out of context is potentially injurious if a user’s query is misguided (Eysenback, 2007). These ideas place a high burden on health educators and content developers and should inspire conservatism in selecting content for online consumption and potentially to guide users to consult printed materials before online materials.

Technological developments provide hope for combatting many of the problems discussed above, including lowering user perception of difficulty of using technological devices for obtaining health information. “Reader” devices, such as the Amazon Kindle and the Apple iPad, may provide screen surfaces that allow users to read information with greater ease and efficiency. Further, various personalized and interactive media, such as phone applications (apps) may help direct users to higher quality and relevant health information with reduced effort invested in the proper use of search engines. Additionally, media designed for use with smart phones may help reach audiences without other forms of digital access. These developing technologies hold significant potential for improving online access of health information and thus warrant in depth inquiry from a variety of angles.

Teachers of writing can learn from these particular features of online communication in order to enhance their curriculum development processes. In particular, online curriculums for use with student populations should be tested in “pull models” of information retrieval in order to understand whether the digital technology hinders user experience. The digital technology might lead to increased levels of perceived difficulty or cause users to consume and apply information out of context.

Chapter 3

1. Introduction

In 2013, I conducted a small-scale, original research project in order to learn more about college students' perceptions of difficulty reading Patient Education Materials (PEMs) in print versus online formats. In this essay, I use findings from that study in order to investigate problems with PEMs in online and print formats in order to open space to offer suggestions about best practices for online PEM creation and dissemination. In order to make such recommendations, I rely heavily on two important trends in healthcare: patient-centered care and evidence-based practice.

In what follows, I offer an overview of problems with both print-based and online PEMs. Afterward, I discuss the ways in which patient-centered care calls for the use of personalized and interactive PEM delivery methods when circumstances allow; central to this argument is the idea that personalized and interactive PEM delivery is supported by evidence-based practice. Finally, I discuss considerations that all personalized and interactive online PEMs should attempt to consider, which include a consideration of the situation of online PEMs within a larger framework of digital technologies; the distribution of kinds of digital devices among various populations across the United States; and a distinction popularized by Arthur Kleinman that delineates the boundary between diagnosis of disease and illness experience. In short, the future of PEM delivery calls for smartphone-compatible PEMs, which may often be synchronized with other patient interactions, such as scheduling and billing procedures. These PEMs should also attempt to offer patients personalized and interactive approaches that embody the ideals of patient-centered care.

2. Concerns with print and online patient education materials

Every method of PEM delivery, of course, has both benefits and drawbacks. Arguably, though, patient education efforts should focus on using a delivery medium that is appropriate for the context in question—no single strategy of patient education will work for every patient in every circumstance.

Importantly, my study of PEMs readability indicated that, despite the widespread availability of standard online PEMs, even information seekers who probably have higher than average levels of digital literacy may perceive online PEMs to be more difficult to comprehend than print-based PEMs, especially in scenarios of "pull" information gathering. (It is important to reemphasize the fact that these students' digital literacy levels were not directly tested, but rather were concluded upon through a conceptual argument. Thus, the conclusion that they have higher than average levels of digital literacy is somewhat tentative.) This level of perceived difficulty is a significant hurdle for online PEMs, but patient-centered approaches (considered in section three) may help mitigate this concern.

Additionally, online health information queries can be misdirected due to the "self as source" user error phenomenon: in "pull" models of information gathering, users bring prior biases to their search procedures. These biases often lead users to retrieve incorrect or irrelevant information that is not representative of the healthcare field's best available health information.

> For example, entering "rapid cure for lung cancer" in a search engine leads to qualitatively different articles on cancer than entering "small cell carcinoma

> treatment," and a search query including the phrase "evidence that X is caused by Y" will return preferably documents confirming that indeed X is caused by Y (even if it is not true), thereby presenting a biased search result that confirms the bias in the recipient. (Eysenback, 2007, p. 129)

Further, users often perceive online information as deriving from unreliable sources (Fox, 2000; Flanagin & Metzger, 2007). In many cases, such user perception is justified: the relative ease and lack of accountability or peer review associated with online publishing lowers quality standards for PEMs. Many users are aware of these concerns and thus approach online PEMs with at least some skepticism.

Conversely, print-based PEMs derive credibility from their sanctioned distribution from places that are generally considered to provide reliable sources of information (e.g., hospitals, doctors' offices, or other health centers). Patients may infer that medical professionals implicitly approve of the PEMs provided in their offices. However, despite the "built-in" approval of many print PEMs, print PEMs generally fail to reach a significantly large population when compared to the wide range of online PEMs (Eysenback, 2007). This phenomenon is a natural consequence of information gathering procedures in the context of a health center in comparison to the context of an online search; in the latter case, the search is only restricted by availability of Internet access and the user's choice of search terms. However, in the former case, the information is restricted to those individuals who visit the health centers where the PEMs are located at the time of their visit.

Print-based PEMs are also unable to add the audio or video elements that are sometimes included in online PEMs. This additional use of media can help reach audiences with various learning styles and strengths. Further, print PEMs cannot include interactive or personalized elements, such as those emerging in many online PEMs (discussed in sections three and four).

Finally, in-person patient education that comes directly from nurses, doctors or other medical professionals, though generally considered credible and highly responsive to individual patient needs, is limited for obvious economic reasons. The cost of direct patient education in the form of skill and content teaching sessions from medical professionals exceeds the cost of other forms of patient education (Funnell, 1992, p. 141). Online or print-based PEMs can be reproduced and distributed with relative ease. Also, patient educators may not be immediately available to provide patient education consultations when patients desire information, whereas print and online PEMs, once they have been provided for the patient, are essentially always available for patient viewing. Online PEMs have the further advantage of being retrievable whenever the patient has Internet access.

3. Patient education materials under patient-centered models of care

Healthcare in the United States has become increasingly influenced by patient-centered models of care, which are often associated with a "medical home" (Nutting, Miller, Crabtree, Jaen, Stewart, & Stange, 2009, p. 255). Additionally, modern healthcare is increasingly influenced by evidence-based medicine (EBM) (Altman, 2000, p. 3276). An understanding of patient-centered models of care and EBM can help inform the process of PEM development.

Patient-centered care models can be traced to George Engel's "biopsychosocial model" and McWhinney and Levenstein's "patient-centered clinical model."

> Engel proposed a 'biopsychosocial model' as an antidote to medicine's increasing biological and molecular reductionism, arguing that the disciplines of psychology and the social sciences were as pertinent to medical research and practice as were the traditional basic biological sciences usually taught in the medical curriculum (Brody, 2009, p. 51).

McWhinney and Levenstein's similar patient-centered clinical model asked doctors to investigate "the patient's experience of the episode of illness, along with whatever practical consequences the illness and the fear of potential outcomes posed for the patient's life" (Brody, p. 52). This latter line of inquiry encouraged physicians to develop empathy for patients' life experiences, both as individuals and as members of various communities. The patient-centered clinical model also helped physicians foster an understanding of patients' feelings, as well as their reasoning and decision-making processes; these concepts are essential for providing patients with clear and appealing care plans.

The idea of patient-centered care also derives from increased access to health information and multiple outlets for obtaining care. Patients often "shop" for healthcare from multiple providers. In turn, successful providers must follow supply and demand models of care, thus centering care around the patient (Robinson, 2008, p. 602). Proponents claim that patient demand for patient-centered care is a natural consequence of increased access to health information and the growing availability of treatment options. Patient demand also aligns patient-centered care with pull models of information gathering, and thus, online PEMs function as paradigmatic examples of patient-centered patient education because of their wide breadth, searchability, and competition for market shares.

Patient-centered approaches have also repeatedly led to positive outcomes. Little (2001) concluded that patient-centered approaches increase patient satisfaction and enablement, while reducing symptom burden and rates of referral (p. 908). Piette, Weinberger, & McPhee (2000) found that patient-centered interventions led to fewer symptoms of depression, greater self-efficacy to conduct self-care activities, and fewer days in bed because of illness (p. 228).

Patient-centered care is often closely associated with a "medical home," a concept that originated in a 2004 report titled "The Future of Family Medicine." Though medical histories were used putatively to inform various specialists of a patient's potentially disparate conditions, specialists remained largely uninformed of a patient's overall health. The report proposed that care should be patient-centered and each patient should have access to a personal medical home where all elements of their care are coordinated. Specifically in the medical home model, "steps must be taken to ensure that every American has a personal medical home that serves as the focal point through which all individuals—regardless of age, sex, race, or socioeconomic status—receive a basket of acute, chronic, and preventative medical care services" (Brody, p. 54). In the context of patient education, a medical home can help patient educators personalize PEMs for individual patients that take their overall health—rather than an isolated condition—into account.

The medical home model provides both patients and medical professionals additional security and has led to improved standards of care. Rosenthal (2008) claimed that medical home models have demonstrably improved societal health in many settings across multiple countries (p. 427). Personalized care offered through a medical home may allow patients to better understand their diagnoses and treatments, while affording medical professionals a comprehensive view of each patient's medical conditions, thus reducing the chance that any particular facet of care is overlooked.

For example, the diverse medical treatments that many patients undergo can lead to drug interactions, which can produce inexplicable or misleading symptoms. Symptoms resulting from drug-interaction processes are often mistaken as indicative of conditions that do not apply to the patient in question. For a more concrete instance of this problem, consider the following scenario. The combination of various organ transplant rejection medications can sometimes lead to heart arrhythmia that might be mistakenly symbolic of unrelated—and nonexistent—cardiovascular problems. If information is not provided about transplant drugs in such a case, the patient faces a very real concern of receiving treatment for a specious health concern.

Arthur Kleinman pointed out an important distinction between illness and disease that helps elicit patient-centered care and may help inform future models of online, interactive PEMs. For Kleinman, illness referred to a patient's experience with a medical condition, while disease refers to a clinical diagnosis that describes the medical condition in question. "Calling for renewed attention to patients' lived experience of symptoms, I emphasized the illness–disease distinction and proposed that by eliciting lay explanatory models through eight questions, clinicians could understand illness experiences and so provide care as well as cure" (Kleinman 2013, p. 1376). Kleinman focused on the importance of distinguishing between persons with a rich internal mental life and biological organisms whose machinations can be described and predicted by a deterministic medical model. Kleinman's eight questions follow:

> [1] What do you think has caused your problem? [2] Why do you think it started when it did? [3] What do you think your sickness does to you? How does it work? [4] How severe is your sickness? Will it have a short or long course? [5] What kind of treatment do you think you should receive? [6] What are the most important results you hope to receive from this treatment? [7] What are the chief problems your sickness has caused for you? [8] What do you fear most about your sickness? (Kleinman, Eisenberg, & Good, 1978, p. 147).

The questions that Kleinman proposed may actually be useful in the initial query stage when patients gather health information in online contexts. An online health portal, such as WebMD, may benefit from tailoring user searches based on some of the above questions to avoid misdirection or error through "self as source." Integration of these questions into health portal search engines would function as an interactive diagnostic tool to help patients find relevant search results. However, the addition of such questions may also allow the patient introspective inquiry into the nature of their illness experience, rather than focusing on mere clinical description of disease. This self-reflection may bring some of the patient's latent concerns to attention and possibly provide direction for future conversations with health professionals that help strengthen patient-provider relationships and empower patients to hold proactive roles in their treatment plans.

A final trend in healthcare, evidence-based medicine (EBM), may also help guide the future creation of interactive PEMs. “Evidence-based medicine (EBM) refers to a shorthand version of clinical epidemiology that clinicians can use to evaluate and apply research results in medical practice” (Henry, 2006, p. 187). Patient-centered approaches, such as the use of interactive or personalized online PEMs, can also be studied in an evidence-based framework.

Evidence-based studies can measure various parameters of sample populations who have been exposed to certain PEMs to predict whether they will produce desirable health outcomes. For instance, “belief improvement” can be measured before and after exposure to a PEM to understand whether the PEM led to a positive change in belief about a health topic (McClune, 2003). Other end user evaluation measures include “acceptability” and “comprehension.” And as discussed above, measures of “perceived difficulty” and other parameters outlined by the health belief model can serve as evidence to help predict health-related behavior. “Readability” is yet another evidence-based measure that can be applied to PEMs; observations of lower reading grade levels may provide at least some measurable correlation to the success of PEMs.

4. Considerations for creating online PEMs

As my discussion above indicates, many factors influence patient receptivity to PEMs. Understanding the cultural context of digital access and digital divides, as well as the specific digital tools that health information seekers and healthcare providers use, may help contribute to the successful production and distribution of online PEMs.

Additionally, considerations of patient-centered care that emphasize the distinction between illness experience and diagnosis of disease may help to improve online PEMs.

Online PEMs are part of a larger, evolving system of digital tools that help health systems manage patient care; PEMs may have a higher likelihood of positively influencing patient behavior when coordinated with other care efforts. Hill (2010) noted that “in large part, the digitalization of hospitals has been an evolution: beginning in the business office, moving to admissions, expanding to support nursing, and emerging as a tool for physicians” (p. 95). This system of digital tools also includes applications such as electronic medical records (EMRs), appointment scheduling databases, patient billing programs, and patient intervention techniques. Patient interventions include reminders (by phone call, text message or email) to take medication, encouragement to exercise, and similar personalized efforts to improve patient health. Online PEMs may be designed and distributed with greater efficiency when seen as related to these additional tools. Coordinating patient education efforts with, say, patient intervention or scheduling may prove to be an effective strategy to educate patients. Coupling patient education with these activities lowers the patient’s perceived inconvenience and perceived time expense: the PEM is delivered directly to the patient, thus there is no additional information-gathering effort required on the patient’s behalf.

In this sort of coordinated care effort, online PEMs are part of a “push” model, which eliminates barriers to PEM use (e.g., perceived inconvenience and perceived expense). In contrast, when patients operate a search engine to find health information, online PEMs are “pulled” from websites; the pull process often proves prohibitive due to patients’ levels of digital literacy; prohibitive time and energy constraints; and reduced perception of source credibility. As described above, source credibility is lower in online searches than situations where the information is presented directly by a health system or health center (Fox, 2000; Flanagin & Metzger, 2007). In coordinated care efforts where PEMs are coupled with sanctioned health system activities, even online PEMs can accrue the extra credibility of being associated with a health center.

Further, the Internet-enabled devices through which users gain Internet access varies widely across populations. Internet PEMs, despite their shortcomings, have the potential to reach many people that may not have access to print PEMs or patient educators because of 85 percent of all Americans go online (Duggan & Smith, 2013). Of these Internet users, smartphone Internet access may be of particular interest for the purposes of patient education, especially for underserved and minority populations. 57 percent of all Americans now go online using a mobile phone and 34 percent mostly use their phone to go online. Duggan and Smith refer to this latter population as “cell-mostly Internet users” (Duggan & Smith 2013). The Pew Research Center has been tracking “cell-mostly Internet users” since 2011, finding that young adults, non-whites, the less educated, and the less affluent are cell-mostly Internet users (Duggan & Smith 2013).

> [S]ix in ten Hispanics and 43% of African-Americans are cell-mostly Internet users, compared with 27% of whites…. Some 45% of cell internet users with a high school diploma or less mostly use their phone to go online, compared with 21% of those with a college degree…. Similarly, 45% of cell internet users living in households with an annual income of less than $30,000 mostly use their phone to go online, compared with 27% of those living in households with an annual income of $75,000 or more. (Duggan & Smith 2013, p. 2)

Rainie of the Pew Internet and American Life Project (2013) noted that smartphone Internet access can help close the gap in a number of pronounced digital divides between groups such as non-Hispanic whites and minority groups, such as blacks and Hispanics. Additionally, digital divides between socioeconomic classes and populations with stratified levels of education may be minimized through the strategic use of smartphone applications. Seventy-four percent of whites have broadband access, while only 64 percent of blacks and 53 percent of Hispanics have broadband. However, when the same user groups are measured for *either* broadband *or* smartphone access, the gap narrows: 80 percent of whites have broadband or smart phone access, while 79 percent of blacks and 75 percent of Hispanics have broadband or smart phone access (Rainie, 2013). When smartphone access is introduced into the equation, general levels of access increase while digital divides between whites, blacks and, Hispanics shrinks considerably.

Clearly, online PEMs that are also compatible with smart phone use reach a larger percentage of the population in general, as well as a significantly higher percentage of some minority populations. To the extent that users can successfully navigate and glean information from mobile pages, smart phones help increase digital access for many populations.

Stuart Selber has noted problems specific to smartphone and other mobile applications: disability access poses a concern worthy of exploration. In particular, new media technologies (e.g., tablets, readers, and smartphones) are often not developed with disability access in mind. Selber attributes this problem largely to the fact that new media technologies require a translational process that is not present when making print works accessible for disabled populations.

> In fact, e-books complicate access issues by introducing a layer of mediation not required of print books, or at least one that is more complex and abstract than those of technological antecedents. With print books, providing alternatives means (to a great extent) translating texts into Braille or audio formats. Starting to work with these translations is a rather straightforward operation: you open the cover and read in Braille, or press play and listen to the narrator (Selber 2011, p.3).

Audible menus and text-to-speech functions are emerging that should help make new media technologies more accessible, but compliance has been slow. In fact, “[t]he United States Department of Justice shares these very real concerns, and thus encouraged American university presidents, in a June 2010 written memorandum, to avoid e-book requirements until e-book devices are compliant with the law” (Selber, 2011, p. 4). Though these concerns have been voiced about university education, analogous problems may face patient education. PEM developers should take care to make sure that online materials conform to the Americans with Disabilities Act of 1990.

The extent to which health information can be effectively digested in the smaller format of a smart phone screen or with lower resolution is a relatively unexplored topic that warrants future attention. Selber concluded that screen size influences reading ability; smaller screens led to reading difficulties due to problems with spatial orientation (Selber, 2011, p.4).

Online PEM designers should make sure that PEMs are designed speicifically with smartphone use in mind, rather than simply transferring a text designed for a full-size screen to a smartphone or reader. Screen resolution should also be taken into account: reader attention will wane in cases where only a lower resolution screen is available.

Finally, patient-centered efforts can help patients engage more fully in the process of patient education. Kleinman's eight question lay explanatory model (discussed in section three) can help improve interactive and personalized online PEMs by both increasing the extent to which care is patient-centered and by avoiding incorrect diagnoses. Kleinman's eight question model adds to the spirit of patient-centered approaches by elevating the importance of patient illness experience. Under this model, patients document their unique experiences through their own words, which helps mitigate the extent to which those experiences are overshadowed by clinical documentation and diagnosis. Use of these questions may also help avoid "self as source" errors by circumventing problems resulting from patients incorrectly self-diagnosing through the use of online searches or other PEMs. Though patients may still freely inquire into the nature of their disease, their inquiry can be guided by more extensive information about their condition, which can be gleaned through their own answers to Kleinman's eight questions.

Patient-involvement in treatment plans and the decision styles of physicians can influence patient care. Many patient populations prefer to take a more active, autonomous role in their treatment; physician decision-styles that emphasize patient involvement in treatment plans have led to improved results in breast-cancer patients (Mandelblatt, 2012). Patients feel increasingly empowered to involve themselves in their healthcare decisions when provided with information about their conditions that they perceive to be understandable, credible, relevant, and considerate of their experience with disease or illness. Recently, evidence-based studies have attempted to demonstrate how patient-centered models of decision making can be used to dispel the paternalistic view that an abundance of information will deter patients from choosing the medically "correct" treatment plan (Gummersbach, 2013).

In practical application, Kleinman's eight-question model can prove useful in patient registration or in refining search engine queries. The answers that patients provide about their experience with their health concerns can be used in multiple ways, each of which enhances patient-centered care. Two categories of information might be gleaned from these questions: information about the patient's illness experience and information to help patients find relevant PEMs and to allow them to express their feelings about their illness experience. Further, systematic collection of this data can be useful for healthcare research that helps bring to light recurring patient attitudes and beliefs about various health conditions. This information can in turn be useful in structuring patient-centered care programs, such as informational sessions and support groups. Incorporation of the eight question lay explanatory model into patient education may also encourage patients to reflect about the nature of their illness, their personal goals and future direction.

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