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Constructing Health Narratives: Patient Feedback in Online Communities

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by

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ABSTRACT

This project examines user-generated health narratives through corpus analysis of 246 reviews posted on Midwestern Hospital's Yelp page. Understanding how different stakeholders act and interact within online health communities models a shift in new conceptions of health, and provides evidence of health ecologies' ability to determine patient perceptions of care. Documents produced by users in these health communities represent health narratives comprised of a user's health experience, that user's treatment perceptions, and the community's perceptions of the user's experience. Author uses corpus methods to interpret user trace data and rhetorical moves embedded in health narratives. Findings suggest that users who interact with the Yelp community produce different health narratives than less engaged users. Understanding how different stakeholders act and interact within online health communities models a shift in new conceptions of health, and provides evidence of health ecologies' ability to determine patient perceptions of care.

THEORIZING HEALTH NARRATIVES

Conceptions of health communication are changing, and now more than ever, patients share and receive health information in online communities. These communities enable patient health writing and feedback in ways that current provider-administered feedback routes do not facilitate. There is much interest in mainstream media about what these online communities are doing to health communication (Cha, 2016; Carroll, 2016). However, scholars of Professional and Technical Communication (PTC) and Rhetoric of Health and Medicine (RHM) have only begun to study this writing, and how patient writing can improve health outcomes. Online writing is often subjected to reader suspicion or dismissed outright as "trolling" (Pavia, 2013; Hartley et al, 1999). But for patients who have endured health experiences that produced negative feelings, having their writing dismissed this way can have serious consequences. If we accept that writing is a form of identity work, then giving patient writing credence as a form of narrative reinforces the importance of patients' experiences.

Constructing Health Narratives: Patient Feedback in Online Communities theorizes health narratives and their production using corpus methods. First, I link this particular research area to overarching research problems identified by PTC and RHM scholars. I then explore scholarship on narratives and their creation to argue that the writing in one particular online health community should be considered a form of narrative. Further, I connect this study to multidisciplinary scholarship on patient-centered care and narrative health. I argue that PTC and RHM scholars can claim this particular definition of health narratives to better study patient voices and experiences. I then explain factors spurring the creation of health narratives, including declining trust in healthcare providers and the opportunities of e-health communities. I examine how health narratives are written and used to change health

communication. Finally, I argue that patients, healthcare providers, and scholars can benefit from theorizing health narratives in this way.

Lack of Trust in Healthcare Providers

A flawed understanding of science and its role in policy and public discourse has led to distrust of science's ethos. While scientists are the most obvious victims of this shift, they are not alone. Healthcare providers too were once recognized as saviors, people who understood different worlds than ordinary people (Stein, 1990). Yet increasing transparency has given citizens access to many scandals: price-gouging pharmaceutical companies (Smith, 2016), expensive yet inadequate health insurance plans (Brill, 2013), and increasingly unequal care between the haves and have-nots (McLean & Datar, 2014). Although these industry scandals have caused many patients to seek second opinions about their own treatment options, more widespread anxiety comes from new conceptions of healthcare. Like science, healthcare suffers from communication problems. When the public does not understand the ways that healthcare providers are communicating with them (Burleson, 2014), they begin to distrust healthcare providers and the information provided by them. They seek other options.

Patients recognize and respond to healthcare in many ways, increasingly online. Though hospitals offer patients some limited opportunities to give feedback, patients also respond to their treatment outside of these sanctioned feedback routes. Available scholarship suggests that patient satisfaction surveys given to patients do not solicit the type of feedback patients want to give (Ranard et al, 2016), and so patients go elsewhere to write about their health experiences instead. Patients already go online to learn (Owens, 2011; Willerton, 2008) about their health experiences, so they are equipped to tell their own stories online as well. This project examines how the means of encouraging communication between patients and healthcare providers are flawed, and how new feedback routes that patients take signal a shift to a new understanding of health; an understanding I term health ecologies. Furthermore, this project finds that the

documents created by these health ecologies are tangible evidence of this shift, and asks what patients, healthcare providers, and patient advocates have to gain if we too adopt this model.

Sharing Wicked Problems in PTC and RHM

Healthcare shares wicked problems with other 21st century institutions. The various actors in a healthcare systems are stuck in a conceptual model that moves relentlessly forward, restoring health that was lost (Sacristán, 2013, Table 1). Science faces a similar discursive problem—the idea of constant progress (Golinski, 1998). Yet in both these institutions, most of the actors concerned are aware that systems do not actually work this way. PTC scholars have identified similar conceptual shifts from modernism to "nonmodernism." Latour (1993) writes memorably, "if we have never been modern...the tortuous relations we have maintained with other nature-cultures would also be transformed" (p.11). PTC scholars have since moved away from the nature-culture divide, re-conceptualizing the National Science Foundation's grant proposal and funding process (Moeller & Christensen, 2010), paleontology (Northcut, 2011), risk communication (DeVasto et al, 2016), and technical and professional communication itself (Rivers, 2008). RHM scholars have also studied how moving to a nomodernist conception of health impacts actors, writing about prions (Reeves, 2011) and military diagnoses (Lindsley, 2015), among others. Nonmodernist approaches to health communication are growing more popular, and there is more recognition of the benefits of nonmodernist treatment options.

Defining Narratives

Narratives happen as an individual attempts to negotiate reality. Scholarship of narratives then sees narratives as a way of isolating individuals' beliefs (Boje, 2001). Narratives are constructed as those beliefs are tested against experiences, perceptions, and other narratives. The "memory work" of these complex mediations offer insights into an individual's identity (Brady & Schreiber, 2013) and how that identity responds to other influences. While narratives can be spoken, written, or visually communicated accounts, this project limits the narratives studied to written accounts only. Writing about experiences, composition

theory informs us, links those experiences to one's identity (Lauer, 2009), and makes those experiences seem more real. In this context, many patients write narratives to construct their own version of an experience. This desire to create alternative versions can be explained by the philosophical desire to blur the artificial line between word and world (see Hanna & Harrison, 2004). Many patients therefore feel that their experience is more important because it is written down.

Many scholars have offered conflicting definitions of narrative. Rudrum (2005) reviews them, pointing out that narratives have been required to be representations of one event, two events, a sequence of events, non-contradictory, logical, and chronological (pp. 195-196). Working from Aristotle's *Poetics*, many scholars report that narratives have beginnings, middles, and ends (Altman, 2008; Wei & Wei, 2006). Others have pointed out that disjointed or incomplete writing can also be considered narrative (Moran, 2013; Salvo, 1999). In particular, Salvo (1999) writes that requiring narratives to be linear retellings has dangers when grasping the scope of the problem, in his case, study of witness narratives of the Holocaust. A more flexible approach to narrative comes from Barthes's (1975) explanation of an "infinite variety of forms" (p. 237). Perkins & Blyler's (1999) suggestion that narrative in professional communication is a "means of being and acting in the world" is relevant here as well (p. 4). If narratives occur in many forms, and are considered to be patients' ways of meaning-making and knowledge work, then the writing in this online community can be considered narrative. Patients write about health experiences online; this writing is their representation of what happened—their narrative.

Individuals write health narratives when they perceive their identities as patients being challenged. In a healthcare context, narratives come into being when patients' experiences differ from their expectations. As Mol (2002) writes, patients continually enact and re-enact their illness. Threats to a patient's enactment may happen when, for example, health information professionals (e.g. general practitioners, specialists, emergency room doctors) offer different diagnoses of the patient's condition. The impetus for forming a narrative to contest this treatment can be found by returning again to composition

theory, specifically to Corder (1985) who wonders what happens when narratives conflict with each other. Narratives function as arguments in this context for the individual's identity and the factors that constructed their experience (Swarts, 2007). Studying narratives as rhetorical moves helps scholars identify patient values and ideologies (Phelan, 1996). As patients write narratives, they enact these values and ideologies, as well as their patienthood, in the face of perceived conflict.

Multidisciplinary Contributions to Narrative Scholarship

Medical humanities scholarship discusses the importance of patients formulating health narratives as a way of understanding health experiences. Many medical humanists study patient writing as a form of therapy (Peterkin & Prettyman, 2009). Education methods suggested by medical humanities scholars include therapeutic journaling or creative writing about health experiences. Yet relatively little scholarship has been done regarding the actual content of health narratives. That is, most scholars accept that the creation of health narratives is important for patients and providers (Lederman, 2016), but very few health narratives have actually been studied. Given that the purpose of narrative creation is to assert an argument for a user's identity as a patient, this project acts as an audience for these arguments.

These new conceptions of care are not new to the health industry. While “health narrative” is not a particularly common term, some medical schools now offer programs in “narrative health” (Columbia University, n.d.) Social science scholars have begun exploring narrative health and its possible benefits to patient treatment outcomes (Sools, 2012; Charon, 2006). Similarly, patient-centered care is a common approach (Garber, 2011; Borycki et al, 2014). Patient health narratives and the systems that produce them circulate control over health, from patient, to provider, to system, back to patient. Studying these health narratives is a way of observing how patients enact control over themselves. To this end, health narratives become agentic acts by their authors and can be integral in a person's health decisions. Writing the health narrative has allowed the patient to better understand their experience.

Healthcare providers play a significant role in constructing patient's health narratives due to

emerging social inequalities. Studies of care models show that there are barriers to patient engagement (Gagliardi et al, 2008). Among these barriers is the belief that patients may use their newfound agency to bother healthcare providers with subclinical disorders or untreatable conditions (Cromme et al, 2016). Health narratives do more than placate angry patients. Even if a patient's condition is not treatable, an ecological understanding of care demands that providers treat the patient and their health identity as important and worthy of being cared for. Often health measures that place more power in the hands of patients draws concern from social justice advocates, who stress that it is necessary for administrators to understand patient experience (Lohmeier Law & Saunders, 2016) and that patients are too often pressured to seem "deserving" rather than empowered (Hushke, 2014). These concerns are not unfounded; if patients gain better treatment outcomes through writing narratives, then conceivably their healthcare providers do not need to keep improving their health. Yet healthcare remains precarious, expensive, and difficult for many to obtain. An ecological understanding of care can balance these concerns as it mediates the identities of patients and providers.

By examining the contents and users who created health narratives in one online community, this project helps Rhetoric of Health and Medicine (RHM) scholars understand what concerns patients have within healthcare settings. It also has insights for scholars of professional and technical communication (PTC) who seek to understand online writing and community.

E-health Communities

Patients access much health information online, and share information in burgeoning online health communities. E-health communities have been documented by PTC and social sciences scholars (Dedding et al, 2011; Brit & Hatten, 2016), and so research suggests that sharing health experiences is an important factor in patient engagement, and in asking patients to participate in policy making (Adams, 2011). When patients share their health experiences online, they are able to understand what kind of care they received, and the kind of care they wished to receive. As they learn about the range of healthcare options available

to them and to others, they begin to explore this gap. When other users comment on those health experiences, they further validate perceptions of care. That those health writings are the result of community writing projects is significant evidence of a shift to an ecological understanding of healthcare and health experiences (Jennings et al, 2016). The texts generated by these online health communities, or health narratives, reveal more about patient perceptions of care.

Narratives constructed by these online health communities provide many opportunities for research and patient advocacy. In a culture that increasingly calls for patient advocates, PTC scholars faces the challenge of finding ways for users to have better health experiences, and produce better health narratives (Meloncon & Frost, 2015). Many factors construct a health narrative, including the health experience itself, a patient's perceptions of treatment(s), and other people's perceptions of that treatment. Health experiences and health narratives differ because health experiences are translated across providers, patients, and finally the community and interface that produces the health narratives. As the experience is influenced by networks of people, technologies, and feelings, the distribution resembles an ecology (Edbauer, 2005). The ecology produces a health narrative and is then cemented by the act of writing the health narrative. Patient advocates can study these health narratives to learn about communication between patients and providers, and how to design better ways to communicate.

Communication design scholarship in this case bridges the gap between the questions healthcare providers ask patients about their treatment, and the answers patients return through both sanctioned and unsanctioned feedback routes. As a sanctioned feedback route, a random sample of patients receive the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. All hospitals that receive Medicare reimbursement funds are required to administer such a satisfaction survey (American Heart Association, n.d.). The thirty-two question survey is administered at random to patients. The HCAHPS is one of the few sanctioned feedback routes for people wanting to discuss their health experience. The results of this particular consumer satisfaction survey are housed in Medicare's Hospital

Compare website, where potential patients can see them (Medicare.gov, n.d.). Yet it doesn't take a scholar to say that the HCAHPS does not provide patients with much of an opportunity to write their health narratives. Conflicts between patients and providers are not resolved in this system; Ranard (2016) found that patients write about significantly more health concerns than given the opportunity to provide feedback about in the HCAHPS. E-health communities then provide better opportunities to observe patients understanding their health experiences than customer satisfaction surveys.

Scholars and patient advocates then return to online health communities to find out how patients resolve conflicting experiences within health narratives. Within these communities, it is possible to observe patients striving to figure out what has happened to them and why it is important. It is also possible to see how hospitals respond (or do not respond) to these arguments. Online health narratives allow observation of how community texts influence hospitals and patients, and how citizen writing mediates corporate medicine. This project discusses the systems that create health narratives, and how those health narratives affect hospitals and patients using multidisciplinary scholarship that conceptualizes health narratives and health ecologies.

Bringing Health Narratives into Being

Health narratives result from resistance to the current healthcare feedback system. Patient satisfaction surveys encourage passive responses to care (Snyder & Engström, 2016) and do not encourage patient narrative or reflection. Similarly, Spoel (2008) found that midwifery information websites maintain a rhetor-audience communication structure. When the patient feels marginalized, they do not feel better or healthier. Although the patients writing health narratives online have received treatment for their injury and have gone home ostensibly treated, they write about wanting more communication from their healthcare providers. Their health narrative is brought into being by this discrepancy between the hospital's idea of treatment and the patient's idea of care (Sacristán, 2013). The current healthcare system treats health as a thing to be regained. Under that model, a provider has only to find the cause of ill health and

treat it. Care becomes the patient's problem. Yet these patients resist the definition of care, and the quality of treatment received.

Writing Health Narratives

The written health narrative is an outcome of the system that produces a health experience. While it may seem intuitive that patients alone write their health narratives, the network is more complex. The patient may enact the narrative (Mol, 2002, p. 32), but the narrative itself is constructed from a web of humans, nonhumans, and technology. When a patient enacts their role as a patient, they are not the only character in the narrative. The subsequent writing then reveals the entire network of the hospital. These characters help a patient perform their patienthood and influence the construction of the health narrative. In many narratives, the other characters are antagonists; perhaps attempts by the author to illustrate violated expectations. Narratives do not all follow this model, yet most do include other characters—other actors, such as family members or friends, doctors, nurses, and administrators in a healthcare setting. In sum, health narratives may be written by the patient or patient advocate, but they are constructed of anyone who helped the patient realize their health identity.

When health narratives are understood as the outcome of a health ecology, the links that hold the system together are illuminated. Nonhuman actors that contribute to health ecologies play important roles in what Mol theorizes is the ontological enactment of disease (2002, p. 36). Many patients privilege human actors and human conflicts as more important. This can result in high rates of patient dissatisfaction with doctors, nurses, and hospital staff. An ecological understanding of care recognizes nonhuman contributions to health. If a patient operates under this model, they would be able to see that many nonhuman actors (i.e. pain, hospital facilities) are more important that conflicts with healthcare providers.

While a patient has always been free to write about their own health, the impetus for many of these health writings is rhetorical; the notion of persuading an audience. As Segal (2008) writes in *Health and the Rhetorics of Medicine*, "Medicine is not only rhetorical as it is reproduced in published texts; it is also

rhetorical as a system of norms and values operating discursively in doctor-patient interviews, in conversations in hospital corridors, in public debate on health policy, and in the apparatus of disease classification" (3). Using this idea, if the purpose of writing a health narrative is to validate one's health identity, then writing the narrative within and for such a system of norms and values would gain more validation. These systems and communities enable written narratives, which means that they must also be given authorship. When community authorship of health narratives is constrained to mere survey results, the system does not enable validation. If it did, patients would not need to write additional health narratives. While patient satisfaction surveys design communication within the boundaries of the survey, unstructured text-entry interfaces allow the patient an unstructured response. The patient is free to tell their health narrative any possible way, and through the nature of the online health community, seek validation.

Usable Health Narratives

Healthcare is an industry crunched for time, oriented around efficiency. While healthcare providers are ethically mandated to help their patients be well, they must also treat hundreds of other patients who they are also ethically mandated to help. Doctors leave many elements of patient communication to nurses and nurse assistants, who are themselves overworked and unprepared to have these conversations with patients (Defenbaugh & Chikotas, 2016). The healthcare industry is then designed to diagnose and treat as efficiently as possible. Efficiency has its own problems, among them one-size-fits-all care, or care for the average patient (Sacristán, 2013). As patients find the efficiency model incommensurable with their own conceptions of care, they try to mediate the difference discursively (Herndl & Graham, 2013). The efficiency model asks only how patients can demand more personalized care from time-strapped providers. Such a question does not even occur in an ecological conception of care, given its notion of multiple ontologies and assemblages.

Under the efficiency model, there is no easy way out of this problem for either patient or provider. Healthcare providers doubt the efficiency model as well as patients, experiencing doubt about both their

diagnoses and their conversations with their patients; they know they are not saviors (Kenny et al, 2010). When patients believe that doctors consider themselves to be saviors, however, and those beliefs are challenged, patients become more distrustful of the efficiency model of care. Thus patients are more likely to to react angrily, at times undermining public health (documented by Kolodziejski, 2014). The efficiency model of healthcare boxes patients and providers into efficient stereotypes.

If the efficiency model of healthcare does not work, then scholars should ask what can be gained and lost by moving to an ecological understanding of healthcare. In this model of healthcare, clear delineations of power and authority are gone. Healthcare providers would have to issue less directives and more negotiations. Health ecologies distribute this power throughout patients, providers, and technologies, across large systems that function to tell stories about patients and their health, and through interwoven systems of narratives to elaborate on the health identity of a public. These systems extend self-efficacy in lieu of efficiency. For an uncomfortable reality is that there are not enough healthcare providers to treat all health problems. Not all patients have clinically treatable conditions. The ecological model of healthcare recognizes and validates the individual expertise of the patient without a healthcare provider's input. Patients can receive more care from their community's shared expertise.

Online health communities enable phronesis, or practical wisdom. Described by Warnick (1989) as “wisdom applied to and made manifest in action,” phronesis circulates around online health communities (p. 305). A patient narrative, validated by other users, becomes an account with its own quantifiable expertise. The narrative then gains standing in the particular health community. The discursive nature of phronesis feeds into an ecological understanding of healthcare, and gives up on a modernist industrialized healthcare fantasy. By situating expertise within a constantly changing community, patients can fulfill Latour's (1993) directive to situate humanism within a “continuous exchange of forms” (p. 138). In a discursive, relational world, a patient may not need a doctor to validate their health experience, but may be content to have community users validate it instead.

Beneficiaries

If health ecologies and the narratives they produce are more useful than current conceptions of care, then the remaining question must be who these health narratives serve. Remember the ambivalent effects of and opinions to patient satisfaction surveys. When communication is designed to produce numbers from something as qualitative as human experience, the pursuit of efficiency may bypass human experience. Instead of designing better patient communication, scholarship on the HCAHPS or other patient satisfaction surveys focuses on case studies of hospitals improving their survey numbers (see Stimpfel, 2016, for example). In contrast, health narratives are largely non-numerical. They are more useful for providing patient feedback because they collect the voices of the patients. Health narratives then serve those who genuinely wish to improve a patient's health experience.

Health narratives should be representative of a patient's entire care experience, across providers, states, and time. They should include input from healthcare providers themselves, who may be able to provide the patient with technical information they lack. Online health communities recognize that patients no longer want to be told what is wrong with them and what to do about it. Patients instead want to engage in their own health ecologies. The health narratives produced by online writing communities are available to be shared and understood by many others. An ecological understanding of healthcare means that new kinds of expertise can be recognized. When healthcare providers encounter these different kinds of expertise, then both patients and providers are able to mediate socially acceptable health outcomes. As patients are able to access more health information, and find that their particular expertise is accepted, they become their own health advocates.

METHODS

Using Corpus Methods to Investigate User Health Narratives

This project attempts to theorize health narratives and their construction within online communities; it is therefore requires a site of research from which a theory can develop. Although the construction of narratives has been well-documented by composition scholars, particularly in literacy narratives (Scott, 1997; Daniel, 1999), not much has been written about what individuals who use online interfaces to construct health narratives. I performed corpus analysis on all of the narratives in the site of research with AntConc, a reporting tool that finds word and phrase frequencies as well as context of search terms within the wider corpus (Anthony, n.d.). Scholars have used AntConc in investigations of large corpora of diverse user writing to study self-placement (Gere et al, 2013), academic discourse (Lancaster, 2016), and first year writing (Aull, 2015). In PTC scholarship, corpus methods have been used to examine student business and professional writing (Wulff & Boettger, 2014). This section overviews corpus methods, describes the site of my research, and explains my research questions, data collection, and data analysis.

Individuals write for many reasons; thus there is a wide variety of writing collected within the research site, and no existing theory to explain any of the data. A different approach to analyzing discourse is then called for to create data-derived explanations. Used most notably by corpus linguistics scholars, analyzing corpora allows scholars to uncover frequency patterns in user writing (Lancaster, 2016). Finding frequency patterns helps researchers identify common threads in the data. The research questions are then answered directly from the users' health narratives and do not rely on scholar coding. This approach allows the researcher "a depth of empirical knowledge that cannot be obtained through other field methods" (Wulff & Boettger, 2014, p. 120). Corpus analysis is the best ideological approach for this

project because it limits the amount of theory, preconceptions, or other limitations I can impose on my data. As I mentioned previously, a major assumption in this project is that individuals would not be composing health narratives if traditional methods of collecting user feedback (i.e. patient satisfaction surveys) had succeeded in validating those health narratives. I assume that this population has a hard enough time making their voices heard. My job as a researcher is not to make it harder for them. Ideologically, corpus analysis ensures that users themselves give shape to the resultant theory.

The necessity of acting as audience and advocate for these users is somewhat countered by an ethical desire to protect their privacy. As scholars writing about online health communication have noted, protecting user privacy is an important consideration for researchers (Koerber & Still, 2008). While users who create health narratives often reveal identifying information like their pictures, names, locations, treatment dates, or treatment types, they may not know how private this information is or should be. Therefore I opted to blind identifying user information beyond the year the health narrative was posted in the research site. This obviously limited data collection. Yet as I considered the value of excluding details like appearance, names, or neighborhood of residence, I realized that too often users are judged by these details, both online and off. Perhaps the reason they are writing health narratives is because their needs were dismissed based on this private data. Therefore limiting the data collected to unidentifiable user information is both ethical and logical.

Yelp as a Site of Research

Users write about health experiences in many places online; I chose Yelp.com because it is popular. Yelp is a site for user reviews of places and services in a given area. Yelp writes that their website hosts 121 million reviews, with 6 percent about health-related businesses ("An Introduction to Yelp Metrics as of December 31, 2016," n.d.). Rhetoric and Composition scholars have studied Yelp reviews as part of extended social media research projects (Ewing, 2013; Spinuzzi, 2012). Furthermore, Yelp gathers user writing into categories based on individual businesses, which facilitates data collection.

Midwestern Hospital

I made up the name Midwestern Hospital to help blind patient identities. I chose Midwestern Hospital, however, by finding the ten largest cities in the United States. Then I used Yelp to search for hospitals within that city. From there, I chose the hospital that had the most reviews. Although most hospitals in large cities have around 200-300 reviews, I chose Midwestern Hospital specifically due its location and population served. According to the information available on Midwestern Hospital's web site, the hospital has nearly 900 beds ("About Us"). According to the information found via the U.S. News and World Report, Midwestern Hospital had approximately 47,000 admissions and 84,000 Emergency Room visits ("Overview"), though U.S. News and World Report does not note the year corresponding to this data. Choosing Midwestern Hospital seemed to fit this project's mission of advocacy.

Choice of Research Questions

Traditional feedback routes are not available to everyone. The most commonly-provided patient satisfaction survey, the Medicare-endorsed HCAHPS is estimated to be administered to only fifty percent of patients, and only thirty-five percent of that percentage respond (Merlino, 2014). In contrast, internet review sites are open to everyone. Yet the problem is not just user response rate, but the questions asked by the feedback tool. Surveys like the HCAHPS are rarely open-ended, providing users with multiple-choice answers to pre-set questions. Users whose experiences do not fit into these categories must go elsewhere to record these experiences. Sites like Yelp place greater importance on the patient's narrative by asking patients to write reviews. Though some unstructured responses on Yelp intersect with topics on customer satisfaction surveys, most patient responses deal with experiences not mentioned on surveys (Ranard et al, 1016). The problem here, is a communication breakdown between patients and providers. Technical communicators can return to online health communities to answer this question. Here we can observe the narratives changing as patients strive to figure out what happened to them and why it is important. Hospital representatives respond to these arguments, further validating these narratives.

Observing health narratives online allows us to see how community texts influence hospitals and patients, and how citizen writing mediates corporate medicine. In this project, I discuss the systems which create health narratives, and how those health narratives affect hospitals and patients. I ask:

- Is there a difference in the topics discussed by more and less engaged members?

User Trace Data

Yelp offers a lot of data for researchers to collect on user behavior within its interface. Called trace data, a researcher can find out how many friends a user has on Yelp, how many other reviews the user has posted, and how many stars (out of 5) the user gave Midwestern Hospital. Furthermore, researchers can view whether other users rated the review "useful," "funny," or "cool." Because the text of the reviews can be copied-and-pasted elsewhere, it is possible to collect the word count of the reviews, as well as include all text from the reviews into a corpus. These details are available for every user and every review; which provides a nice jumping-off point for this project. Indeed, if this research is to be an act of audience and advocacy, studying the information on users themselves would help guide of the narratives users create. I collected all data from 2007 to late 2016 in a spreadsheet, organized by the year the review was posted, how many friends the user had, how many stars the reviewer gave Midwestern Hospital, the word count of the review, and then the review itself. Then I recorded what reactions the Yelp community had to the review.

Analyzing Data

I decided to track word and phrase frequencies with AntConc, a tool for corpus analysis. Developed by Lawrence Anthony as a "toolkit for concordancing and text analysis," AntConc is designed to "find and reveal patterns in language" (Tang, 2013). With corpus analysis, I considered words and phrases to be representative of user thoughts, and I used AntConc to sort through patterns in the available data. Using AntConc to analyze the corpus of health narratives let me see immediately what words were

most commonly used. From there, I could easily return to the data to see in which contexts those frequently used words were used. I found this approach to preserve narratives throughout data analysis.

Dividing Corpora by User Friend Counts

I used Microsoft Excel's data analysis tools to calculate median totals for friends, reviews posted, and stars given to Midwestern Hospital. Calculating the median numbers finds the true middle numbers in a data set, and the resulting totals are less likely to be biased by large or small outliers, as an average calculation would be. After I found that the median number of friends users had on Yelp was 5, I divided users into two groups; those with 5 or more friends, and those with 4 or fewer friends. I will call the former group "engaged users" and the second group "less engaged users." I then divided the entire corpus based on these designations.

Analyzing Corpuses

After dividing the corpus of user reviews by user friend counts, I was left with three corpuses; the master corpus, the corpus of engaged user reviews, and the corpus of less engaged user reviews. I ran word and phrase frequency tests on each corpus to find the 100 most commonly-used words, 2-word phrases, and 3-word phrases. Searching for multi-word frequencies (called n-grams) allowed me to further contextualize what users are reporting. After I had found these word and phrase frequencies, I returned to the original text of the reviews using the concordance feature of AntConc and my spreadsheet. I read the text of the reviews to check my conclusions.

LIMITATIONS

This study is limited by a limited sample and by lack of user verifiability, among other concerns. Considerations from these limitations will be further described.

Limited Sample

This project examines 246 health narratives found on Yelp. This nearly 900-bed hospital serves approximately 131,000 patients per year (U.S. News and World Report, "Overview"). If this information is correct, these 246 health narratives represent 0.2% of the total patients handled by this hospital per year. This is a very small sample size.

Patients do not use Yelp as their only audience for health narratives. Users tag Midwestern Hospital in their Facebook posts, write about their experience in Twitter posts, post pictures on Instagram, review the facility on Google+, and write about Midwestern Hospital on reddit.com. Other health narratives no doubt exist in more places online, or even offline in journals, text messages, or phone conversations.

While there seem to be more Midwestern Hospital narratives on Yelp than on other platforms, the small sample size is not an undue limitation due to this project's grounding in advocacy. This project seeks to serve as audience for these users, who in many cases are so focused on telling about their experiences that they ignore or subvert the purpose of the Yelp interface. Even though this project uses some quantitative methods, the project itself is not quantitative; the findings provide a larger audience for these users' health narratives, and further theorize health narratives as a topic of study for scholars in RHM and PTC.

Lack of User Verifiability

There is no way to tell whether the users writing health narratives on Yelp are actually patients or not. While some post pictures of themselves, or write about hard-to-invent experiences, others tell general stories of long Emergency Room wait times, which is surely a common theme in hospitals everywhere. I have mitigated this limitation as much as possible, by using only reviews Yelp itself recommends. Yelp uses its own rater reliability algorithms (“What is Yelp's recommendation software?”) when deciding which rater reviews to privilege and which to hide on the site.

RESULTS

Common Themes

Given that many users scored Midwestern Hospital a 1 out of 5, common themes in the review analysis are negative. Many users mention long wait times, particularly in the Emergency Room, but also in diagnosis times. More users explain that Midwestern Hospital was unhelpful in resolving their health situations, particularly in customer service and billing. While some users place the blame for this lack of care on doctors and nurses, users are generally positive when discussing hospital staff. While a few users name unhelpful doctors and nurses specifically, users are generally grateful to doctors and nurses for providing care. Users assign blame more commonly to a more generic administration, or hospital bureaucracy.

N-gram Analysis and Keywords

Searching the 100 most common one-grams, bigrams, and trigrams provided hospital-related keywords that showed up most frequently in the data. Choosing keywords rather than using every term from the word frequency list means that results can be focused to the actual factors that construct a health experience and narrative. While terms like “Midwestern Hospital” were not a surprise, some frequently used terms provoked some concern, like the keyword “pain”, used 88 times in the corpus. Note that keywords like “pain” and “surgery” disappear from bigram and trigram analyses of the corpus. For more information, see Tables 1, 2, and 3 for one-gram, bi-gram, and tri-gram analysis of the entire corpus on the next page.

Table 1: Keywords in entire corpus one-gram analysis

Rank in Word Frequency List	Frequency in Corpus	Word
24	266	hospital
36	167	er
41	160	doctor
56	131	midwestern
69	109	doctors
81	90	patient
83	88	pain
88	86	staff
89	85	nurse
93	79	nurses
94	79	surgery
96	76	insurance

Table 2: Keywords in entire corpus bi-gram analysis

11	84	the hospital
27	56	the doctor
38	47	told me
56	36	the staff
64	34	a doctor
70	33	the nurse
72	33	this hospital
73	33	this place
80	31	at midwestern
87	30	the doctors
88	30	the nurses
98	28	midwestern hospital
100	28	the waiting

Table 3 shows tri-gram analysis of the entire corpus and is shown on the next page. Tri-gram analysis finds the most frequently used three-word phrases in a given corpus and in this case includes phrases like “to the er,” “the waiting room,” and “had to wait.” See below.

Table 3: Keywords in entire corpus tri-gram analysis

1	35	to the er
6	23	the waiting room
11	18	in the waiting
12	18	the midwestern hospital
14	17	the emergency room
18	16	in the hospital
19	15	in the er
27	13	to the hospital
41	10	had to wait
72	8	see a doctor
75	8	the nurses were
77	8	this hospital is
82	7	a ct scan
85	7	at the hospital
90	7	care of me
91	7	doctors and nurses
94	7	hospitals in the

Differentiating Between Engaged and Less Engaged Users

Calculated by median user friends, engaged users have five or friends, while less engaged users have four or fewer friends. Out of 246 user reviews, 120 were posted by less engaged users. Here are the star totals posted by less engaged users:

Table 4: Less engaged user star ratings of Midwestern Hospital

Star Rating	Frequency by Less Engaged Users
1	65
2	16
3	7
4	11
5	20

127 reviews were posted by engaged members of the community. The distribution of stars awarded by engaged members of the Yelp community differs from the stars awarded by less engaged users. Table 5 shows the amount of stars awarded by engaged users of the Yelp community. See below.

Table 5: Engaged user star ratings of Midwestern Hospital

Star Rating	Frequency by Engaged Users
1	24
2	15
3	10
4	34
5	44

Differences in N-gram Analysis Between Engaged and Less Engaged Users

When the corpus is comprised of 120 less engaged users, many n-grams remain the same as in the general corpus. Given the lack of difference between single-word frequencies, they will not be provided in the results section. With bi-gram and tri-gram analysis, some new results enter the data.

Table 6: Selected bi-gram analysis of less engaged user corpus

Rank in Word Frequency List	Amount of times phrase appears in corpus	Phrase
85	15	insurance company
87	15	my mother

Table 7: Selected tri-gram analysis of less engaged user corpus

26	7	the ob gyn
36	6	my insurance company
38	6	the insurance company
43	5	have to pay
58	5	should have been
67	4	a collection agency
96	4	my mom s
98	4	out of pocket

Table 8: Selected bi-gram analysis of engaged user corpus

59	19	the best
60	19	the next

Table 9: Selected tri-gram analysis of engaged user corpus

33	7	i ended up
38	7	taken care of
56	5	a few days
74	5	on a sunday
76	5	the next day
85	4	a ct scan
88	4	a teaching hospital
90	4	about an hour
93	4	au bon pain

Percentage of Reviews

It is not a surprise to learn that most user reviews (90 out of 246) were 1 star reviews, denoting negative experiences. The conventional rationalization is that users do not bother to post a review unless they are negatively motivated, although this thesis attempts to resist this idea. Indeed, 5 star reviews ranked second-highest (64 out of 246).

Table 10: Number of 1,2,3,4,5 star reviews with percentage of total

Number of Stars	Number of Reviews	Percentage
1	90	36%
2	31	13%
3	17	7%
4	44	18%
5	64	26%

DISCUSSION

Unanticipated Use of Interface

Yelp user behavior and writing contrasted with the site's intended purpose. When a user visits the Yelp interface, "write a review" is located in the top left-hand corner and is probably the first thing a user will read.

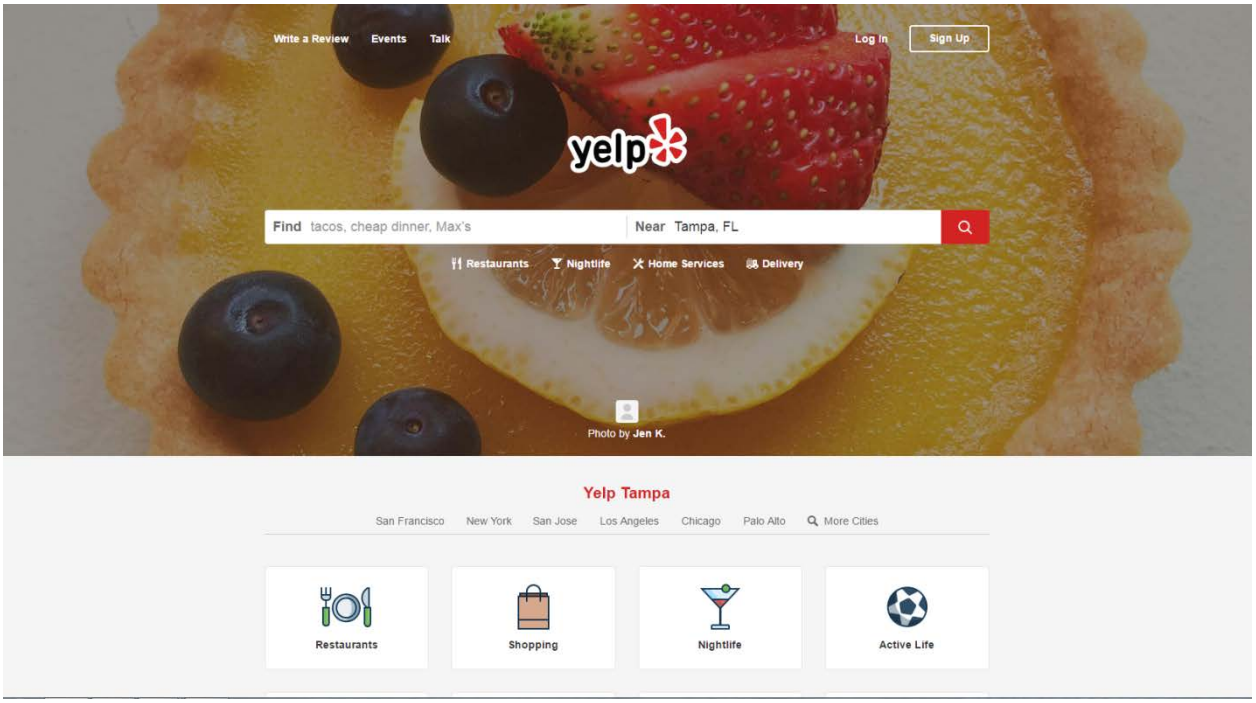


Figure 1: "Write a Review" is located in the top left-hand corner

Yet many user "reviews" did not seem like reviews. If the purpose of a review is to observe and critique something for others (Mackiewicz, 2010, p. 5), then many of the users' writings were at odds with the interface. Instead of asserting credibility or expertise (Mackiewicz, 2009, 2010), or even of showing signs of writing for an audience (i.e., a user who explicitly wrote "I would not recommend Midwestern Hospital"), many users simply wrote about their health experience. This phenomenon is not unheard of; user reviews and comments sections online have been deemed vitriolic. Yelp itself acknowledges these

user behaviors. The site filters user reviews. About this practice, a video on Yelp says, "...not all reviews are created equal. Which is exactly why we recommend some reviews and not others. Every Yelp review is automatically evaluated by Yelp's recommendation software based on quality, reliability, and user activity on Yelp" (Yelp, 2017). During the video explanation, the video shows an image of a review written by a user with 0 friends, who has only written 1 review on the site. A big red X is drawn through the review.

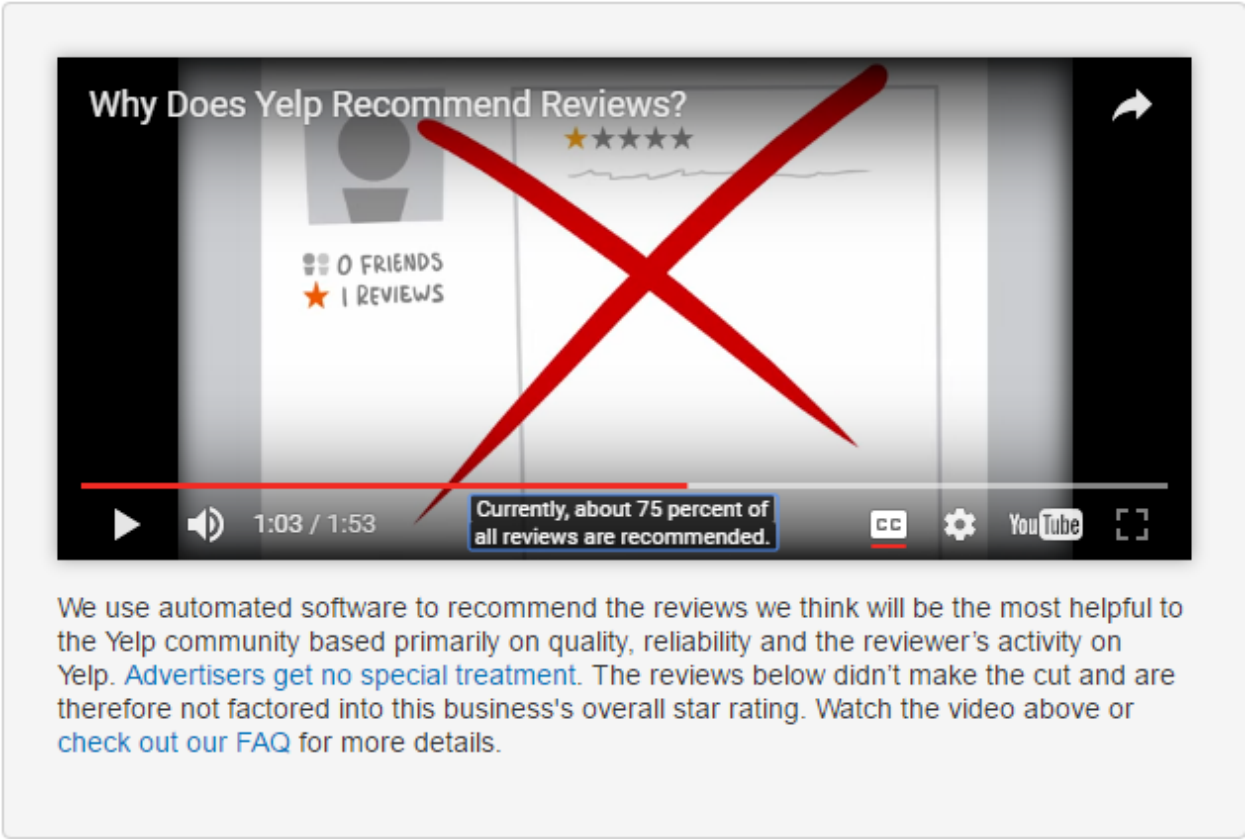


Figure 2: Screenshot showing Yelp's dismissal of users with 0 friends and few reviews

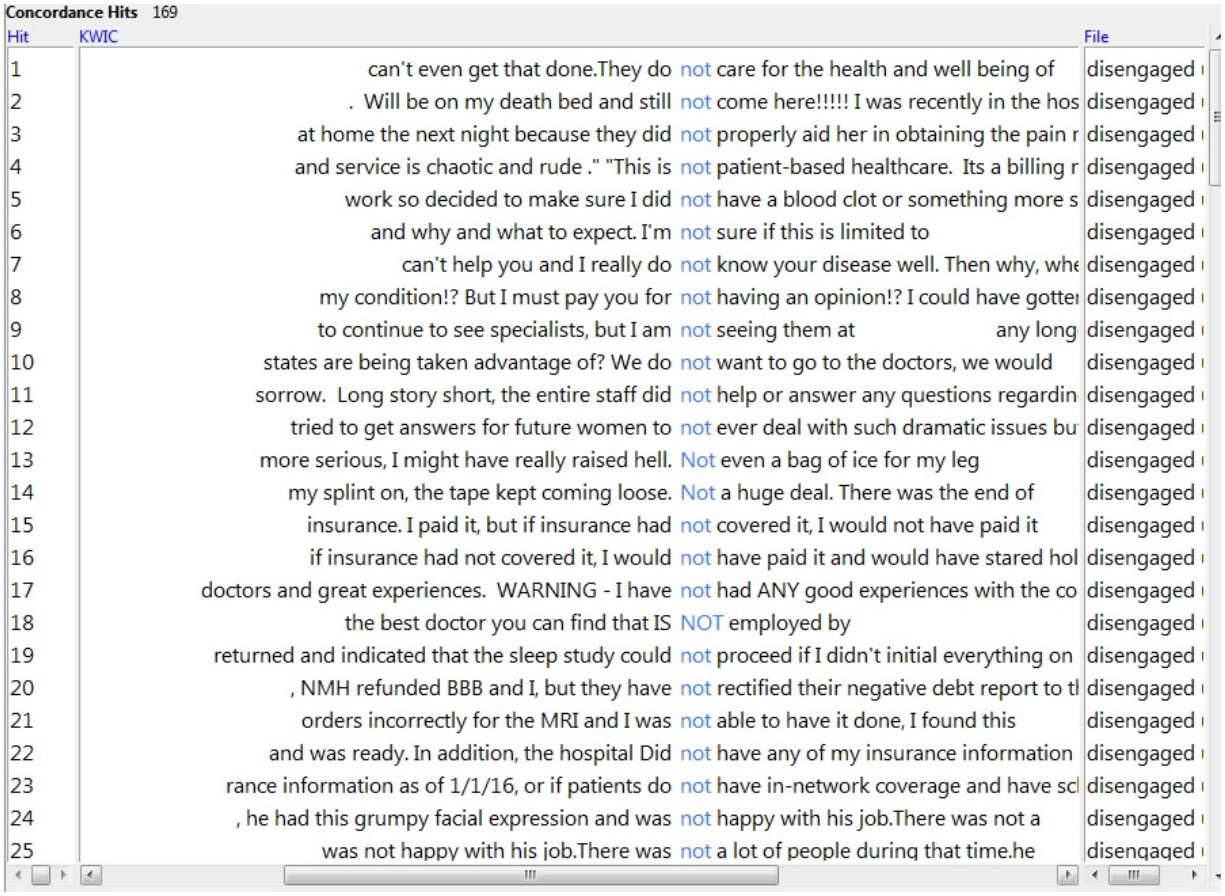
Some reviews of Midwestern Hospital are actually reviews, but many are written by users whose characteristics match the review in the image.

Lack of Response from Healthcare Providers

Midwestern Hospital has responded to eight users' Yelp posts in the nearly-ten years of reviews this project collected. Responses are always the same. A customer service representative greets the user, replies that "we're very sorry to hear that," and directs the user to send them a private message with contact information. This seems like a great start to provoking a conversation between patient and provider. However, some of the contacted patients have updated their Yelp reviews to indicate that neither the customer service representative nor Midwestern Hospital had ever contacted them about their experience again. The lack of response from healthcare providers is particularly troubling, and indicates that the seeming gap between patient and provider will not be bridged in the near future. While the public is increasingly demanding new relationships with their healthcare providers, lack of response from providers via these mediums indicates a disparity in the health narratives; a definite patient bias.

Less Engaged Users Do Not Write All Negative Posts On Yelp

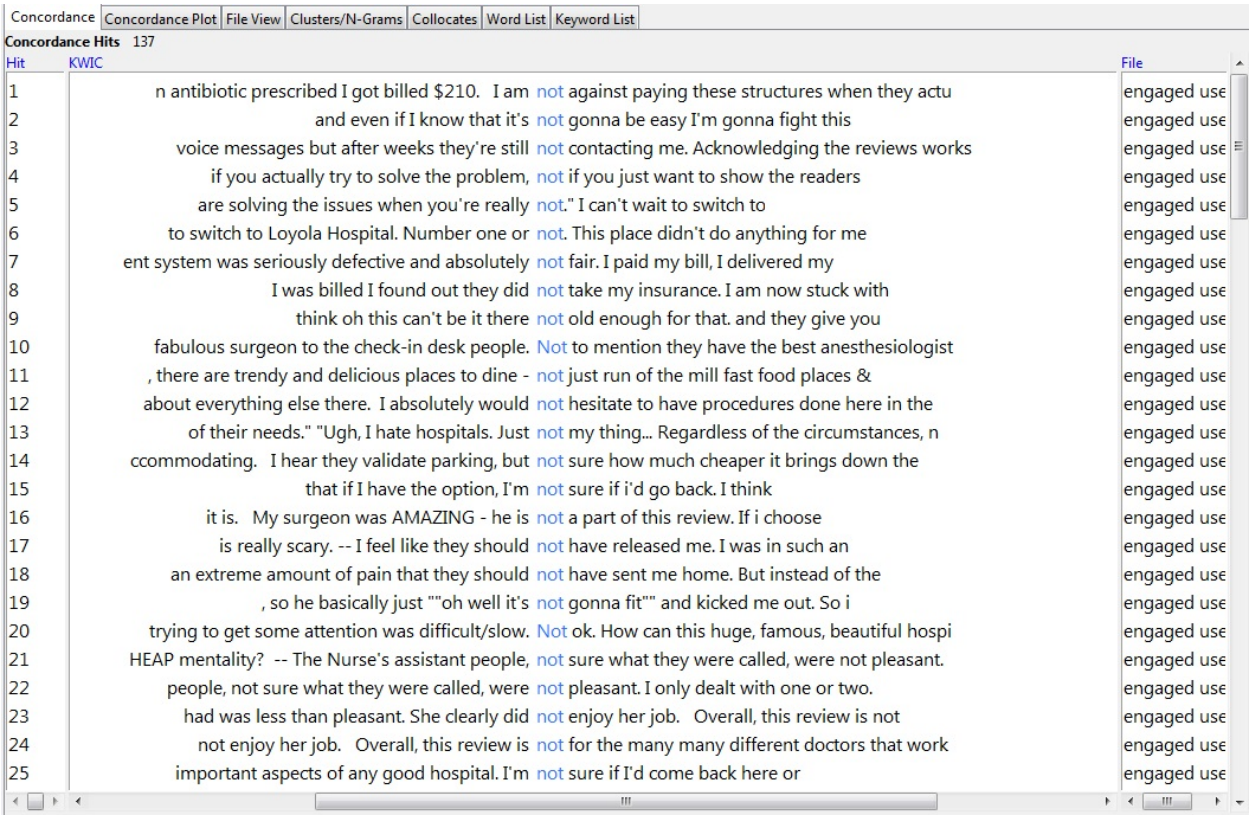
Contrary to popular belief (documented by Ornstein, 2016), less engaged users are not completely negative when writing about their health experiences on Yelp. While 54% of less engaged user posts assign Midwestern Hospital a 1 star ranking, there is a general distribution of stars assigned. N-gram analysis confirms this. Consider the word "not," an indicator of a negative opinion, the most highly ranked negative word within all three corpuses being studied. The word "not" is rarely associated with a good experience, no matter what corpus it appears in.



Concordance Hits 169

Hit	KWIC			File
1	can't even get that done.They do	not	care for the health and well being of	disengaged
2	. Will be on my death bed and still	not	come here!!!!! I was recently in the hos	disengaged
3	at home the next night because they did	not	properly aid her in obtaining the pain r	disengaged
4	and service is chaotic and rude ." "This is	not	patient-based healthcare. Its a billing r	disengaged
5	work so decided to make sure I did	not	have a blood clot or something more s	disengaged
6	and why and what to expect. I'm	not	sure if this is limited to	disengaged
7	can't help you and I really do	not	know your disease well. Then why, whe	disengaged
8	my condition!? But I must pay you for	not	having an opinion!? I could have gotte	disengaged
9	to continue to see specialists, but I am	not	seeing them at any long	disengaged
10	states are being taken advantage of? We do	not	want to go to the doctors, we would	disengaged
11	sorrow. Long story short, the entire staff did	not	help or answer any questions regardin	disengaged
12	tried to get answers for future women to	not	ever deal with such dramatic issues bu	disengaged
13	more serious, I might have really raised hell.	Not	even a bag of ice for my leg	disengaged
14	my splint on, the tape kept coming loose.	Not	a huge deal. There was the end of	disengaged
15	insurance. I paid it, but if insurance had	not	covered it, I would not have paid it	disengaged
16	if insurance had not covered it, I would	not	have paid it and would have stared hol	disengaged
17	doctors and great experiences. WARNING - I have	not	had ANY good experiences with the co	disengaged
18	the best doctor you can find that IS	NOT	employed by	disengaged
19	returned and indicated that the sleep study could	not	proceed if I didn't initial everything on	disengaged
20	, NMH refunded BBB and I, but they have	not	rectified their negative debt report to th	disengaged
21	orders incorrectly for the MRI and I was	not	able to have it done, I found this	disengaged
22	and was ready. In addition, the hospital Did	not	have any of my insurance information	disengaged
23	rance information as of 1/1/16, or if patients do	not	have in-network coverage and have sch	disengaged
24	, he had this grumpy facial expression and was	not	happy with his job.There was not a	disengaged
25	was not happy with his job.There was	not	a lot of people during that time.he	disengaged

Figure 3: Random selected appearances of the word “not” in the less engaged user corpus



Concordance | Concordance Plot | File View | Clusters/N-Grams | Collocates | Word List | Keyword List

Concordance Hits 137

Hit	KWIC			File
1	n antibiotic prescribed I got billed $210. I am	not	against paying these structures when they actu	engaged use
2	and even if I know that it's	not	gonna be easy I'm gonna fight this	engaged use
3	voice messages but after weeks they're still	not	contacting me. Acknowledging the reviews works	engaged use
4	if you actually try to solve the problem,	not	if you just want to show the readers	engaged use
5	are solving the issues when you're really	not	." I can't wait to switch to	engaged use
6	to switch to Loyola Hospital. Number one or	not	. This place didn't do anything for me	engaged use
7	ent system was seriously defective and absolutely	not	fair. I paid my bill, I delivered my	engaged use
8	I was billed I found out they did	not	take my insurance. I am now stuck with	engaged use
9	think oh this can't be it there	not	old enough for that. and they give you	engaged use
10	fabulous surgeon to the check-in desk people.	Not	to mention they have the best anesthesiologist	engaged use
11	, there are trendy and delicious places to dine -	not	just run of the mill fast food places &	engaged use
12	about everything else there. I absolutely would	not	hesitate to have procedures done here in the	engaged use
13	of their needs." "Ugh, I hate hospitals. Just	not	my thing... Regardless of the circumstances, n	engaged use
14	ccommodating. I hear they validate parking, but	not	sure how much cheaper it brings down the	engaged use
15	that if I have the option, I'm	not	sure if i'd go back. I think	engaged use
16	it is. My surgeon was AMAZING - he is	not	a part of this review. If i choose	engaged use
17	is really scary. -- I feel like they should	not	have released me. I was in such an	engaged use
18	an extreme amount of pain that they should	not	have sent me home. But instead of the	engaged use
19	, so he basically just ""oh well it's	not	gonna fit"" and kicked me out. So i	engaged use
20	trying to get some attention was difficult/slow.	Not	ok. How can this huge, famous, beautiful hospi	engaged use
21	HEAP mentality? -- The Nurse's assistant people,	not	sure what they were called, were not pleasant.	engaged use
22	people, not sure what they were called, were	not	pleasant. I only dealt with one or two.	engaged use
23	had was less than pleasant. She clearly did	not	enjoy her job. Overall, this review is not	engaged use
24	not enjoy her job. Overall, this review is	not	for the many many different doctors that work	engaged use
25	important aspects of any good hospital. I'm	not	sure if I'd come back here or	engaged use

Figure 4: Random selected appearances of the word “not” in the engaged corpus

“Not” is ranked twenty-second in the complete corpus, twentieth in the less engaged user corpus, and twenty-fifth in the engaged user corpus. When looking at word neighborhoods around the word “not,” readers can see that there is no great difference between what the users are writing. This indicates that less engaged users do not write all negative reviews. A possible explanation for this may be that Yelp filters user reviews already, and this project does not use reviews not recommended by Yelp

Less Engaged Users Are More Likely To Mention Insurance, Billing, Or Payment

Results of bigram and trigram analysis show that engaged users rarely mention hospital bills, while billing shows up as a high frequency item in the less engaged user corpus. Most commonly associated complaints about billing for engaged users include unnecessary testing, insurance not paying the patients’ bill, high prices, and insurance confusion. One lucky engaged user writes “I have never had a problem with the billing either.” The disengaged users tell a different story, with more reporting frustration with the bureaucracy of an enormous hospital. Speaking about Midwestern Hospital’s billing department, users

term it a “billing machine” and “scam-ola.” They also report similar confusion over their bills, negligent billing practices, high prices, and a few report their bills being sent to collections. These complaints are particularly concerning given that they occur more frequently to less engaged users. Since Yelp is likely to hide less engaged users, their complaints about billing practices may be hidden from their audience.

Users and Advocacy

Less engaged users are slightly more likely to write as advocates for the health experiences of others, as bigram and trigram analysis of less engaged users suggests. Reading through user reviews challenges this finding; 20 out of 120 less engaged users wrote reviews explicitly for other people, while 12 out of 127 engaged reviewers wrote reviews for other people. Rather than claim that the difference is significant, it is more interesting to examine advocacy narratives. Users normally identify their status as advocate early in the narrative, then proceed to write about the treatments the person for whom they are writing the narrative endured. Advocacy narratives tend to provoke polar reactions from the writer; either they are extremely grateful to Midwestern Hospital (“They saved my wifes [sic] life…”) or they are extremely angry at what they see as ill treatment. One of the longest health narratives in this corpus, at 920 words, provides a numbered list of doctors, staff, and patients who endangered the writer’s 95-year-old mother. While users may include advocacy narratives as an appeal to *pathos*, they do not receive significantly more “useful” votes from the community. Perhaps this is because the Yelp interface does not support sympathy votes. Readers can rate reviews “useful,” “funny,” or “cool,” but for more varied reactions, they would have to contact the reader directly.

Places in the Hospital

Many user narratives are concerned with issues of place, and places in Midwestern Hospital. Note that “hospital” and “er” are the most frequently used keywords in the entire narrative corpus. Assuming that “hospital” is the most frequently used due to users writing the name in their narratives, I examine places in the hospital that users particularly attribute to constructing their health experiences.

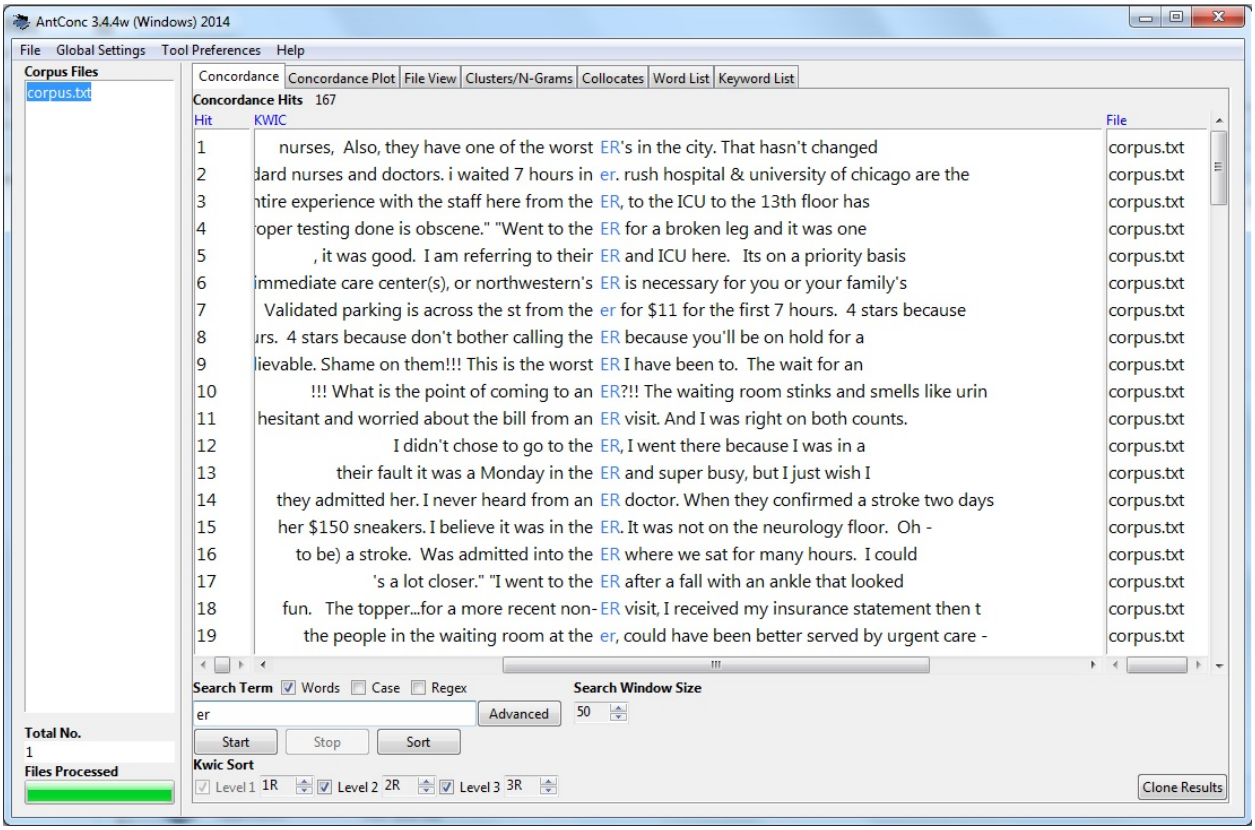


Figure 5: Results of concordance search for “er” in AntConc

According to *ProPublica*, Midwestern Hospital’s Emergency Room treats a very high volume of patients and has an average wait time of 48 minutes before being seen by a doctor. While these narratives seem to indicate the patient waited hours before treatment, dipping into *ProPublica*’s patient pathways research supports these assertions.

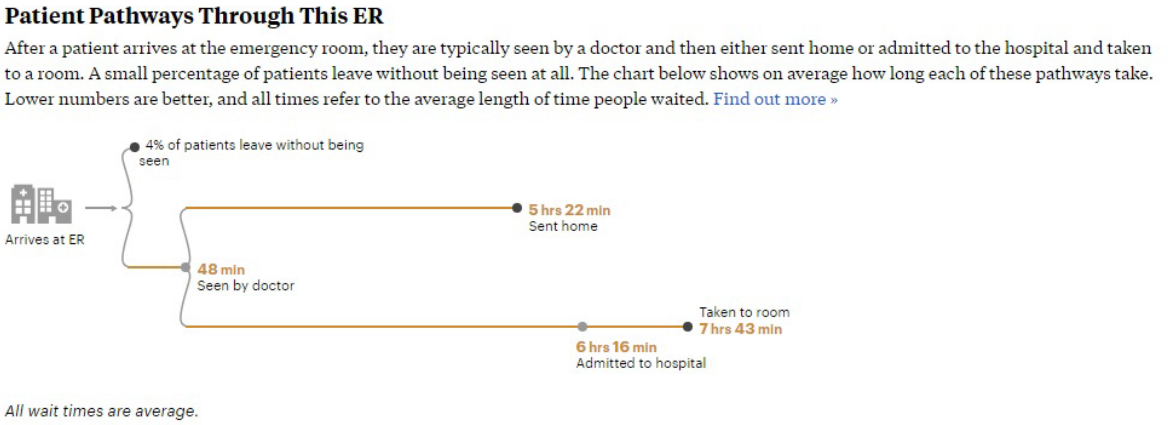


Figure 6: *ProPublica*.org, “ER Wait Watcher” for Midwestern Hospital

On average, patients spend nearly five and a half hours in the ER before being sent home, six hours before being admitted to the hospital, and nearly eight hours before being taken to a hospital room. The amounts of time that patients spend in the Emergency Room certainly justifies its high frequency in corpora of both engaged and less engaged users. Despite frustration with long wait times, user populations do not provide many descriptions, positive or negative, of the Emergency Room. While some note that it is disorganized or unclean (as might be expected of an ER reported to treat 83,000 patients per year), most patients are occupied with the wait times and the lack of immediate treatment. The ER as a place, then, is not necessarily the most influential factor that patients write about. Instead, the factor patients write about is waiting in the Emergency Room, surrounded by their pain and others in pain. Their narratives detail their frustration with inaction.

Audience Awareness

Though these health narratives are posted ostensibly as reviews on Yelp, audience awareness cues are surprisingly rare in the corpus. Audience awareness cues might include recommendations to go to or avoid treatment at Midwestern Hospital. Out of 246 reviews, there were only 28 recommendations, only about 11% of the total. Engaged users offered 17 recommendations, 13 of which were positive. Less engaged users offered 11 recommendations, 10 of which were directives to avoid Midwestern Hospital. Instead of specifically recommending the audience to go to or avoid Midwestern Hospital, users were more likely to write whether *they* would return or not. They revert back to their own experience rather than direct their readers.

Although authors may steer away from specific recommendations to seek or avoid treatment at Midwestern Hospital, they are not shy about issuing directives to readers. Though many authors use “you” in their narratives to refer to their own experience, many write directly to an audience of fellow Yelp users, telling them to bring an advocate, or to be prepared to wait. Notably absent from most narratives is the idea of Midwestern Hospital as the audience. Only one reviewer writes directly to Midwestern Hospital, after a

customer service representative contacted them on Yelp. The reviewer writes, “Acknowledging the reviews works only if you actually try to solve the problem, not if you just want to show the readers that you are solving the issues when you’re really not.” Though moving, this is the only review that directly addresses Midwestern Hospital, showing that users may not anticipate their healthcare providers ever reading or responding to their health narratives. Users do not expect Midwestern Hospital to be part of this community, or conversation.

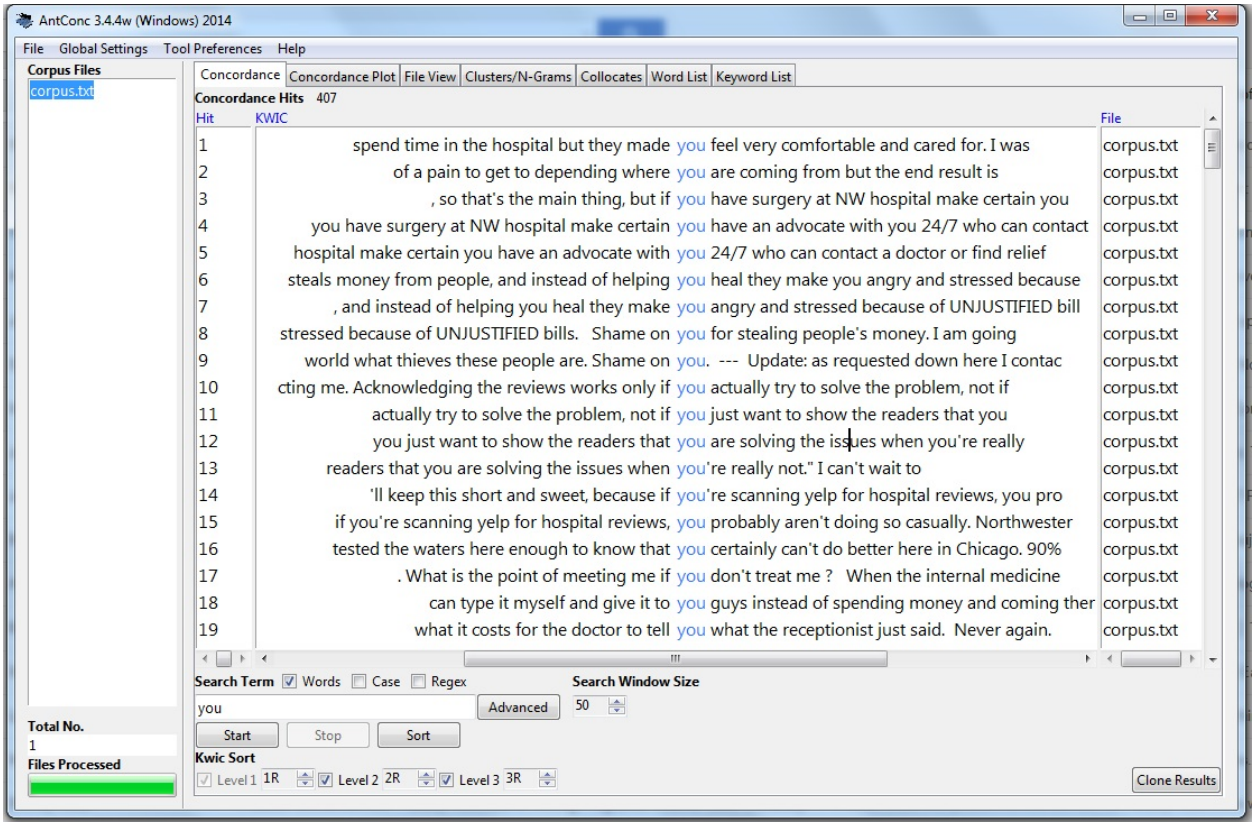


Figure 7: AntConc Concordance analysis for the word “you”

Different User Groups Act Differently on Yelp

Users use Yelp’s technology differently; some boast large friend followings and write many reviews. Other users have no friends and write only about Midwestern Hospital. After dividing these groups into engaged users and less engaged users, I found some differences in user health narratives. Engaged users tended to write more positive narratives in terms of stars assigned to Midwestern Hospital. Engaged users also complimented doctors, nurses, and staff more often than did less engaged users. While

less engaged users do tend to assign less stars to Midwestern Hospital, their narratives indicate good reason for less stars; billing woes and long wait times in the emergency room. Succinctly, less engaged users may be less engaged because they feel as though the health community is not participating in the partnership. Narratives of less engaged users, and their unwillingness to write more reviews or friend more Yelp users may be a symptom of perceived isolation.

Common Health Concerns

Both user groups in this study wrote often about billing, insurance, and the high prices of care. These concerns were followed by places in the hospital, particularly the emergency room. Concerns generally turned to compliments by the time users reported being moved to an actual hospital room, however. Users frequently write about pain, and the doctors and nurses who alleviate that pain. While most users write positively about medical professionals, they direct ire towards other hospital personnel, like transporters, administrators, customer service representatives, and members of the billing department.

IMPLICATIONS

This project attempted to theorize health narratives and the health ecologies that produce them. It then attempted to find health narratives and health ecologies outside of theory. In the 246 reviews of Midwestern Hospital posted on Yelp, this project found actual health narratives that meet the definitions and theoretical requirements expressed throughout this paper. To be a health narrative, this project stipulated that the user be attempting to negotiate reality through writing, that the user might use the interface to inform possible readers about their own experience rather than review Midwestern Hospital for a generalizable audience, and that the user construct their experience of multiple factors. This research found that Yelp reviews of this particular hospital meet these standards. Theory is thus applied to this particular community. Understanding these reviews as health narratives can help PTC and RHM scholars see evidence of a cultural shift to an ecological understanding of healthcare.

Given this understanding, this project implies what factors are most important in health narrative construction. Among these factors is the user's perception of health as an experience, not simply as a gift borne by the doctor-savior figure from Modernist lore. Evidence of this shift is found simply by recognizing these 246 reviews as health narratives; if patients did not believe their experience needed to be negotiated, then they would not write them. That they do, however, signals existence of a second theoretical construct this project has introduced: health ecologies. Health ecologies are signaled by new conceptions of healthcare, and of the patient-provider communication dynamic. Health ecologies exemplified in these health narratives include the many factors that construct these patients' writing. Patients write about a multitude of humans and nonhumans in flux within these health narratives. This project analyzes the ecologies that produced patient health experience, but also realizes that a different kind of ecology published them. Ecological thinking also guides theorizing of the Yelp community and the

types of narratives it produces. By expanding on these ideas, the project produces implications for interfaces that mimic ecologies and the complex systems that produce communication.

As patients see and comprehend these systems, they demand similar conceptions from other communication systems in their lives. This is evident from the negative words some patients use to characterize the distributed oversight and paperwork of a large hospital. Due to their expanded awareness of healthcare and what healthcare should be like, patients want to see these complex systems sync. Studying health narratives of patients at Midwestern Hospital reveals particular communication problems like discontinuity between hospital billing interfaces and customer service breakdowns. Studying health narratives also shows what patients appreciate about their experience at Midwestern Hospital; a high level of expertise from doctors and nurses, and the facilities where treatment occurs.

FURTHER RESEARCH

This project has attempted to show health narratives circulating within health ecologies, but these are two nascent theories to RHM scholars. Further research might conceptualize and build on definitions of health narratives and health ecologies, while grounding theory in actual user texts. Scholars could also look into applications of health narratives, and find out whether they enhance patient treatment outcomes. This research problem requires more work into assessment of improved treatment outcomes or patient communication. Once assessment of health narrative impact has been theorized, health narratives themselves can be further valued.

This project has theorized and found evidence to support a conceptual shift in the nature of healthcare. As RHM scholars find more evidence to support health ecologies, or ecological conceptions of science, technology, or business, then we must also consider whether this shift in perceptions has any tangible benefit. Future research might ask what health ecologies do, and how they reconfigure problematic conceptions of care in health communications. PTC scholars might ask how they can theorize health ecologies within empirical case studies, and how the results of these case studies challenge conceptions of treatment that do not recognize the massive role of social factors in constructing healthcare.

PTC scholars should do further research into communication design, and particularly to design of interfaces to collect health narratives. Researchers who wish to be advocates for special populations must also realize that users post health narratives online and reveal identifiable patient information; more work must be done to protect user/patient privacy and to educate users as to the uses of health information they reveal. Yet researchers also walk the fine line of needing users to share their health narratives. Scholars need to find new ways of engaging users, and of designing interfaces that anonymize confidential information while providing scholars with enough information to answer other research questions

associated with this project.

Further research might be done in designing participatory health communication. Many users want healthcare providers to read or respond to their narratives. Yet healthcare providers do not, for what are probably a multitude of reasons. Scholars should find out what these reasons are, and ask what would make hospitals and healthcare providers devote more time to communicating with patients. Building participatory technology is a particular talent of PTC scholars; many online interfaces reflect an ecological understanding of user communication. These interfaces should be used to guide creation of new health communities that embraces this conception.

Scholars should realize that assessment and identifying tangible health benefits to treatment outcomes and patient communication is only one goal of this project. Studying health narratives not only may help healthcare providers fix communication problems within a particular user population, but will help populations of patients and providers reconfigure power dynamics. Health narratives help patients negotiate their reality. Through these negotiated realities, patients perceive that they reclaim power perceived lost. PTC and RHM scholars can bring these perceptions to power within communities, mediating the relationship between patients and providers.

CONCLUSIONS

Theorizing health narratives requires understanding of the many factors that construct them. Cultural shifts in healthcare have changed the patient-provider relationship; patients are demanding more communication about their health experiences. When communication between these two populations breaks down, patients negotiate their health experiences through other means. Some do this within e-health communities, which enable users to share their experiences in narrative form with a varied readership. This project theorized health narratives and suggested that their study and the study of the ecologies that produce them could help RHM and PTC scholars engage more users in participatory health communities, and mediate health outcomes for both patients and providers.

To do this, I applied corpus methods to 246 user reviews of Midwestern Hospital on Yelp. I asked what topics users wrote about in their health narratives. After seeing discrepancies in user engagement within this health community, I asked how engaged and less engaged users wrote differently within this particular health community. Some topics are predictable; patient satisfaction surveys ask questions about doctors, nurses, pain and medication, and understanding doctor's orders. Similarly, many patients write about doctors, nurses, and pain. Yet they also write about the process of healthcare and how much time and anxiety it entails. Frequency analysis of the corpus showed that users write often about how much time they spent in the Emergency Room or waiting in general. Frequency analysis also shows that users are worried about billing and inter-departmental communication. Reading the corpus confirms these findings; users write about long wait times and lack of diagnoses from healthcare providers. About billing concerns, users report frustration with knowing when bills will arrive, or the charges associated with their treatment. Patient satisfaction surveys do not ask questions about these topics; perhaps they should if their aim is to engage users.

Although the authors of these health narratives write to an audience of other authors, they are not writing to Midwestern Hospital directly. That they believe Midwestern Hospital as an entity does not care about them or their health experiences is obvious from their writing. Instead, patients report happiness that individual hospital staff members showed concern about their conditions. One patient directly quotes Midwestern Hospital's "patients first" mission statement, remarking "We are scared and tired, sick and alone and yet you make us feel like a number with a dollar sign." If the community circulating around Midwestern Hospital is generally representative of hospital-community relations, then the breakdown of communication between patients and providers is concerning, and should be addressed.

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APPENDIX

1-grams from the entire corpus

Word Rank	Frequency in Corpus	Word
1	2106	the
2	1640	i
3	1435	and
4	1431	to
5	1071	a
6	796	was
7	693	of
8	674	in
9	649	my
10	552	for
11	531	that
12	522	they
13	453	me
14	449	is
15	407	you
16	404	it
17	362	have
18	335	with
19	330	this
20	320	t
21	317	had
22	306	not
23	295	on
24	266	hospital
25	254	but
26	251	at
27	241	be
28	229	s
29	213	there
30	212	an
31	212	are
32	193	she
33	181	so
34	177	if

35	170	as
36	167	er
37	167	when
38	164	get
39	162	we
40	161	were
41	160	doctor
42	158	out
43	157	her
44	156	or
45	151	all
46	149	up
47	145	room
48	144	about
49	144	he
50	143	one
51	142	would
52	134	after
53	134	time
54	133	care
55	131	from
56	131	midwestern
57	130	by
58	127	no
59	126	their
60	125	very
61	125	what
62	124	been
63	122	go
64	121	hours
65	113	just
66	112	here
67	111	told
68	109	do
69	109	doctors
70	107	like
71	107	your
72	106	back
73	103	can
74	98	who
75	98	will
76	97	even
77	95	because

78	94	am
79	93	them
80	93	wait
81	90	patient
82	90	waiting
83	88	pain
84	88	some
85	87	good
86	86	people
87	86	said
88	86	staff
89	85	nurse
90	83	more
91	82	went
92	79	don
93	79	nurses
94	79	surgery
95	77	could
96	76	insurance
97	76	never
98	76	really
99	76	then
100	75	has

1-grams from the less engaged corpus

1	1107	the
2	778	i
3	734	to
4	715	and
5	542	a
6	368	was
7	359	of
8	322	in
9	310	my
10	293	for
11	282	that
12	268	they
13	248	is
14	230	me
15	216	it
16	215	you

17	197	with
18	196	have
19	180	this
20	169	not
21	157	t
22	150	had
23	148	on
24	130	be
25	125	at
26	121	s
27	118	hospital
28	116	but
29	115	she
30	114	are
31	100	her
32	96	if
33	95	an
34	91	doctor
35	89	when
36	87	as
37	87	there
38	86	would
39	84	get
40	81	one
41	81	out
42	81	so
43	80	their
44	79	or
45	79	we
46	78	what
47	76	no
48	74	after
49	74	care
50	74	up
51	73	told
52	72	by
53	71	he
54	69	were
55	68	been
56	68	er
57	67	northwestern
58	66	about
59	66	from

60	66	patient
61	63	do
62	63	your
63	61	back
64	61	very
65	60	all
66	60	room
67	60	time
68	60	will
69	56	doctors
70	55	who
71	54	hours
72	53	just
73	52	insurance
74	51	can
75	49	even
76	49	them
77	48	go
78	47	any
79	47	good
80	46	said
81	45	like
82	44	bill
83	43	called
84	43	has
85	43	nurse
86	42	wait
87	42	waiting
88	41	could
89	41	don
90	41	staff
91	41	which
92	39	am
93	39	because
94	39	billing
95	39	over
96	39	patients
97	38	never
98	38	people
99	37	also
100	37	only

1-grams from the engaged user corpus

1	999	the
2	862	i
3	720	and
4	697	to
5	529	a
6	428	was
7	352	in
8	339	my
9	334	of
10	259	for
11	254	they
12	249	that
13	223	me
14	201	is
15	192	you
16	188	it
17	167	had
18	166	have
19	163	t
20	150	this
21	148	hospital
22	147	on
23	138	but
24	138	with
25	137	not
26	126	at
27	126	there
28	117	an
29	111	be
30	108	s
31	100	so
32	99	er
33	98	are
34	92	were
35	91	all
36	85	room
37	83	as
38	83	we
39	81	if
40	80	get
41	78	about

42	78	she
43	78	when
44	77	or
45	77	out
46	76	here
47	75	up
48	74	go
49	74	time
50	73	he
51	69	doctor
52	67	hours
53	65	from
54	64	northwestern
55	64	very
56	62	like
57	62	one
58	60	after
59	60	just
60	59	care
61	58	by
62	57	her
63	56	because
64	56	been
65	56	pain
66	56	would
67	55	am
68	54	some
69	53	doctors
70	52	can
71	51	no
72	51	wait
73	48	even
74	48	more
75	48	people
76	48	waiting
77	47	got
78	47	really
79	47	went
80	47	what
81	46	do
82	46	their
83	45	back
84	45	nurses

85	45	staff
86	44	surgery
87	44	them
88	44	then
89	44	your
90	43	didn
91	43	who
92	42	nurse
93	41	dr
94	41	great
95	41	m
96	40	good
97	40	said
98	39	before
99	39	know
100	38	don

Bigrams from the entire corpus

Word Rank	Frequency in Corpus	Bi-gram
1	251	i was
2	197	in the
3	170	to the
4	141	of the
5	128	i had
6	107	and i
7	103	to be
8	97	i have
9	94	the er
10	84	it was
11	84	the hospital
12	79	don t
13	79	that i
14	75	for the
15	73	didn t
16	71	to get
17	69	for a
18	69	it s
19	68	when i
20	66	and the
21	61	if you

22	59	had to
23	57	to go
24	56	and they
25	56	i am
26	56	i m
27	56	the doctor
28	55	on the
29	54	at the
30	53	in a
31	52	i would
32	49	she was
33	48	had a
34	48	was in
35	47	have to
36	47	of my
37	47	this is
38	47	told me
39	46	i ve
40	46	me to
41	44	have been
42	44	with the
43	42	if i
44	41	but i
45	41	was a
46	40	going to
47	40	is the
48	40	one of
49	39	to a
50	37	go to
51	37	i went
52	37	is a
53	36	by the
54	36	i could
55	36	so i
56	36	the staff
57	36	to my
58	35	and a
59	35	have a
60	35	the best
61	35	they are
62	35	was not
63	35	with a
64	34	a doctor

65	34	from the
66	34	on a
67	34	t have
68	33	a few
69	33	in my
70	33	the nurse
71	33	they were
72	33	this hospital
73	33	this place
74	32	can t
75	32	out of
76	32	that they
77	32	they have
78	32	to have
79	32	would be
80	31	at midwestern
81	31	to do
82	31	wasn t
83	31	went to
84	31	you are
85	30	for my
86	30	that s
87	30	the doctors
88	30	the nurses
89	30	time i
90	30	you re
91	29	a lot
92	29	and was
93	29	i got
94	29	the next
95	29	the time
96	28	couldn t
97	28	i can
98	28	midwestern memorial
99	28	on my
100	28	the waiting

Bigrams from the less engaged user corpus

1	102	i was
2	89	in the
3	78	to the

4	76	of the
5	50	i had
6	50	i have
7	49	to be
8	46	and i
9	43	for the
10	42	for a
11	42	the hospital
12	41	don t
13	38	the er
14	38	when i
15	37	that i
16	35	it was
17	35	the doctor
18	35	to get
19	33	it s
20	32	at the
21	32	told me
22	31	and they
23	31	i am
24	30	didn t
25	30	if you
26	29	have been
27	28	and the
28	28	have to
29	28	to a
30	27	on the
31	27	she was
32	27	with the
33	26	i would
34	26	me to
35	26	was not
36	24	had a
37	24	in a
38	24	is the
39	23	this place
40	23	to go
41	22	they are
42	22	this is
43	20	had to
44	20	to do
45	20	was a
46	20	with a

47	19	and a
48	19	i m
49	19	i ve
50	19	one of
51	19	the nurse
52	19	the patient
53	18	by the
54	18	from the
55	18	go to
56	18	going to
57	18	i could
58	18	if i
59	18	is a
60	18	of my
61	17	and that
62	17	can t
63	17	i called
64	17	i will
65	17	it is
66	17	that the
67	17	the staff
68	17	they have
69	17	to my
70	17	was in
71	17	you are
72	16	a doctor
73	16	at northwestern
74	16	for my
75	16	no one
76	16	out of
77	16	t have
78	16	that they
79	16	the best
80	16	the same
81	16	this hospital
82	16	which i
83	15	but i
84	15	but the
85	15	insurance company
86	15	me a
87	15	my mother
88	15	the doctors

89	15	they were
90	15	to see
91	15	went to
92	15	you have
93	15	you re
94	14	a very
95	14	and was
96	14	as i
97	14	back to
98	14	couldn t
99	14	i asked
100	14	i can

Bigrams from the engaged user corpus

1	149	i was
2	108	in the
3	92	to the
4	78	i had
5	65	of the
6	61	and i
7	56	the er
8	54	to be
9	49	it was
10	47	i have
11	43	didn t
12	42	that i
13	42	the hospital
14	39	had to
15	38	and the
16	38	don t
17	37	i m
18	36	it s
19	36	to get
20	34	to go
21	32	for the
22	31	if you
23	31	was in
24	30	when i
25	29	in a
26	29	of my
27	28	on the

28	27	for a
29	27	i ve
30	26	but i
31	26	i would
32	25	and they
33	25	i am
34	25	so i
35	25	this is
36	24	had a
37	24	have a
38	24	i went
39	24	if i
40	24	in my
41	22	at the
42	22	going to
43	22	she was
44	22	to have
45	21	one of
46	21	the doctor
47	21	was a
48	20	a few
49	20	all the
50	20	care of
51	20	i got
52	20	me to
53	20	on a
54	20	time i
55	19	go to
56	19	have to
57	19	is a
58	19	that s
59	19	the best
60	19	the next
61	19	the staff
62	19	to my
63	19	wasn t
64	19	would be
65	18	a doctor
66	18	by the
67	18	i could
68	18	on my
69	18	t have
70	18	the time

71	18	there is
72	18	they were
73	17	i don
74	17	the nurses
75	17	this hospital
76	17	with the
77	16	a lot
78	16	and a
79	16	from the
80	16	hospital i
81	16	is the
82	16	out of
83	16	that they
84	16	waiting room
85	16	went to
86	16	you can
87	15	and was
88	15	at northwestern
89	15	can t
90	15	have been
91	15	me i
92	15	northwestern memorial
93	15	the doctors
94	15	they have
95	15	told me
96	15	with a
97	15	you re
98	14	able to
99	14	and then
100	14	because i

Tri-grams from the entire corpus

1	35	to the er
2	29	i was in
3	28	i had to
4	26	i don t
5	24	i didn t
6	23	the waiting room
7	22	one of the
8	21	a lot of

9	19	i had a
10	19	to go to
11	18	in the waiting
12	18	midwestern hospital
13	17	go to the
14	17	the emergency room
15	17	went to the
16	16	i have been
17	16	i ve been
18	16	in the hospital
19	15	in the er
20	14	and i was
21	14	didn t have
22	14	it was a
23	13	and it was
24	13	i went to
25	13	that i had
26	13	they didn t
27	13	to the hospital
28	13	was in the
29	13	when i was
30	12	and that i
31	12	i have to
32	12	i m not
33	12	the time i
34	12	they don t
35	12	told me to
36	11	and i have
37	11	i can t
38	11	it s a
39	11	this place is
40	11	told me that
41	10	had to wait
42	10	i ended up
43	10	i have ever
44	10	i would be
45	10	i would have
46	10	if you have
47	10	it s not
48	10	that i was
49	10	this is the
50	10	you don t
51	9	a few days

52	9	don t have
53	9	don t know
54	9	for a few
55	9	i said i
56	9	i ve had
57	9	i was there
58	9	some of the
59	9	t have to
60	9	there is no
61	9	they couldn t
62	9	this is a
63	8	and didn t
64	8	and told me
65	8	didn t know
66	8	had to go
67	8	i couldn t
68	8	i had been
69	8	i was told
70	8	i wasn t
71	8	in a room
72	8	see a doctor
73	8	so i was
74	8	the next day
75	8	the nurses were
76	8	they have a
77	8	this hospital is
78	8	this is not
79	8	time i was
80	8	to my room
81	8	was going to
82	7	a ct scan
83	7	able to get
84	7	and was told
85	7	at the hospital
86	7	back to the
87	7	be able to
88	7	but i was
89	7	by the way
90	7	care of me
91	7	doctors and nurses
92	7	going to be
93	7	have to go
94	7	hospitals in the

95	7	i called the
96	7	i have no
97	7	i was not
98	7	i was on
99	7	i will never
100	7	i wouldn t

Tri-grams from the less engaged user corpus

1	14	to the er
2	12	one of the
3	11	i didn t
4	11	the waiting room
5	10	a lot of
6	10	in the waiting
7	9	i don t
8	9	i had to
9	9	i have been
10	9	i ve been
11	9	northwestern memorial hospital
12	9	they didn t
13	9	told me that
14	8	go to the
15	8	i had a
16	8	i would have
17	8	the emergency room
18	8	this place is
19	8	to go to
20	8	went to the
21	7	and i was
22	7	and that i
23	7	i was in
24	7	i went to
25	7	in the hospital
26	7	the ob gyn
27	7	told me to
28	7	when i was
29	7	you don t
30	6	and it was
31	6	didn t have
32	6	i called the

33	6	i have to
34	6	i said i
35	6	it s not
36	6	my insurance company
37	6	that i had
38	6	the insurance company
39	6	they don t
40	6	when i called
41	5	and told me
42	5	and was told
43	5	have to pay
44	5	i had been
45	5	i have ever
46	5	i have no
47	5	i ve had
48	5	i was there
49	5	i was told
50	5	i wouldn t
51	5	if i could
52	5	if i had
53	5	if you are
54	5	if you have
55	5	is the best
56	5	it was a
57	5	see a doctor
58	5	should have been
59	5	some of the
60	5	they told me
61	5	to my room
62	5	to the hospital
63	5	trying to get
64	5	waiting for the
65	5	was told that
66	5	when i asked
67	4	a collection agency
68	4	a few days
69	4	and i can
70	4	and i have
71	4	back to the
72	4	be able to
73	4	by the way
74	4	didn t know
75	4	doctors at northwestern

76	4	every time i
77	4	for my annual
78	4	give me a
79	4	he told me
80	4	hospitals in the
81	4	i came to
82	4	i can t
83	4	i could have
84	4	i couldn t
85	4	i m not
86	4	i told the
87	4	i would not
88	4	if it s
89	4	in a room
90	4	in the room
91	4	it doesn t
92	4	it s a
93	4	it was not
94	4	it would be
95	4	like i was
96	4	my mom s
97	4	of the best
98	4	out of pocket
99	4	t have the
100	4	t have to

Tri-grams from the engaged user corpus

1	22	i was in
2	21	to the er
3	19	i had to
4	17	i don t
5	13	i didn t
6	12	in the er
7	12	the waiting room
8	11	a lot of
9	11	i had a
10	11	to go to
11	10	one of the
12	10	was in the
13	9	go to the
14	9	i would be

15	9	in the hospital
16	9	it was a
17	9	northwestern memorial hospital
18	9	the emergency room
19	9	the time i
20	9	went to the
21	8	didn t have
22	8	i m not
23	8	in the waiting
24	8	to the hospital
25	7	and didn t
26	7	and i have
27	7	and i was
28	7	and it was
29	7	don t know
30	7	had to go
31	7	had to wait
32	7	i can t
33	7	i ended up
34	7	i have been
35	7	i ve been
36	7	it s a
37	7	so i was
38	7	taken care of
39	7	that i had
40	7	time i was
41	6	care of me
42	6	don t have
43	6	for a few
44	6	i have to
45	6	i was on
46	6	i went to
47	6	m not sure
48	6	that i was
49	6	the er and
50	6	the nurses were
51	6	they don t
52	6	this is not
53	6	this is the
54	6	to have a
55	6	when i was
56	5	a few days

57	5	and that i
58	5	as a patient
59	5	at this point
60	5	because i was
61	5	but i was
62	5	doctors and nurses
63	5	going to be
64	5	i got a
65	5	i had an
66	5	i have ever
67	5	i m sure
68	5	i was having
69	5	i was not
70	5	i wasn t
71	5	if you have
72	5	if you re
73	5	me i was
74	5	on a sunday
75	5	t have to
76	5	the next day
77	5	there is no
78	5	they couldn t
79	5	this hospital is
80	5	this is a
81	5	told me to
82	5	up to the
83	5	was going to
84	5	was having a
85	4	a ct scan
86	4	a few times
87	4	a hospital and
88	4	a teaching hospital
89	4	able to get
90	4	about an hour
91	4	and i m
92	4	at the hospital
93	4	au bon pain
94	4	but it was
95	4	didn t know
96	4	don t think
97	4	for me i
98	4	from the time
99	4	have to go
100	4	hours i was