

From the Margins of Healthcare: De-mythicizing Cancer Online

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Abstract: *"From the Margins of Healthcare: The Online Community-Written Diagnosis Narrative" is a deeply personal study in which a breast cancer survivor and participant-observer in the large, online peer-to-peer healthcare community emerges from the silenced margins of medical paternalism to give voice to patients often silenced in traditional healthcare settings. This study examines one online thread, an immediate archive, women's rhetorical history in the making, as a site of feminist praxis through a collaboratively written response to standard medical practice that interrogated top-down policies allowing the silenced to find power and agency.*

Keywords: *healthcare, cancer, survivor, patient advocacy, feminist community building, online support communities*

As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have. The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythicize it. - Susan Sontag *Illness as Metaphor* 7

After my breast cancer diagnosis, I stumbled out of the exam room and headed toward the scheduling desk armed with scribbled notes, a tape recording of my rock-star oncologist describing my diagnosis, and the elaborate treatment plan for the clinical trial on which I was about to embark. Walking down the hall, I said to my husband, "Is there a pamphlet? Shouldn't someone give me a pamphlet? Folder? No? A binder, maybe? Not even a pamphlet?" My husband said, "What kind of pamphlet?" I responded, "I don't know. I don't make the pamphlets. Like a 'So, You've Got Breast Cancer,' pamphlet or a 'What You Need To Know When Coming in for Chemo' pamphlet." Nope. There are no pamphlets. I told the woman who scheduled me for nearly thirty

appointments, “Oh, they didn’t give me a binder.” “They were supposed to give you a binder?” “Weren’t they?” “What sort of binder?” “I don’t know. Isn’t there a binder?” Obviously, I wasn’t communicating well. It turns out, there are no binders. So, I went to the bookstore. There were some books, several in fact, but I wasn’t ready to hear anyone else’s cancer story. I wanted the book to talk to *me*. I wanted it to know what I needed. I wanted to interact with people who knew what I was experiencing, and I didn’t find that in a book. I found it online—not in one story, but in the exchanges among the thousands that gather in the online breast cancer support community.¹

Cancer is complicated, mysterious, and frightening. In *Illness as Metaphor*, Susan Sontag refutes Karl Menninger’s suggestion in his 1963 book *The Vital Balance* that we should abandon names and labels for illnesses because the very term “cancer” can strike fear enough to kill one. It would be better, Menninger had argued, to leave a patient in ignorance than for a patient to be saddled with the confirmed diagnosis of certain death. Unsatisfied with ignorance, Sontag instead urges us to confront illness because the silencing of terms “would mean, in effect, increasing secretiveness and medical paternalism” (7). Gerald Dworkin defines paternalism as “the interference of a state or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm” (1). Even when intentions are noble, and doctors believe “that the person affected would be better off, or would be less harmed as a result of [a] rule, policy, etc., and the person in question would prefer not to

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be treated this way, we have an instance of paternalism" (Dworkin 7).² Sontag counters paternalism with a call for us to understand illness. "The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythicize it" (7).³ In order to de-mythicize we must gather many voices and experiences together to share, inform, and support patients so that they can come to an understanding of illness, and be empowered in the patient-doctor relationship. As this study proves, collaborative diagnosis narratives written in the online breast cancer support community are feminist responses to standard medical practice, and together, they work to de-mythicize cancer by sharing the real experiences of life with cancer from many patients' standpoints. The online breast cancer support community subverts medical paternalism by providing a patient-centered, peer-to-peer forum for empowering patients by de-mythicizing cancer. By informing cancer patients of the realities of many lived, felt experiences of cancer and its treatment, the assumptions and myths of cancer are debunked, and patients are empowered and liberated by information.

2 In *Health and the Rhetoric of Medicine*, Judy Segal tackles the issue of paternalism in her chapter, "The Problem of Patient 'Noncompliance': Paternalism, Expertise, and the *Ethos* of the Physician." Segal concludes that, "In general, we should trust physicians themselves to act on their best knowledge, and we should act on our best knowledge, too, which includes knowledge of what a good idea it often is to take the advice of experts. We all do well to know as much as we can; we cannot all know what doctors know" (152). We should, as Segal argues, respect the expertise of doctors when it comes to medical knowledge, but the online community offers a place to gather knowledge that is born from the lived experience of a variety of patients. I do not mean to suggest that doctors have unkind intentions or simply operate as dictators without taking into account the input of patients. I do claim, however, that patients often feel as though they can't question doctors, and I believe that the online space offers patients a forum outside the real and/or perceived hierarchies of the doctor-patient relationship where discussion can lead to empowerment and liberation.

3 The myths of cancer are too extensive to list, and the size of the online community hints at the individual complexities of the issues covered by a community that far exceeds the confines of simply the medical concerns of patients. Driven by fear, a newly diagnosed patient faces the unknown, and the experiential truth shared by fellow patients addresses the many unknowns of the uninitiated. In the online community, for example, patients learn that you often gain weight from cancer treatment, that reconstruction is far from a "boob job," and many other facets of the experience of cancer that doctors, friends, and family members cannot know unless they too have experienced it.

In *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*, Sandra Harding states that: “The remedy for the inadequate philosophies of science, epistemologies, and methodologies justifying and guiding mainstream research, and the social theories that informed them, according to [feminist standpoint] theorists, was to start off thought and research from women’s experiences, lives, and activities (or labor) and from the emerging collective feminist discourses” (Harding 6). A collective discourse of women’s experience with breast cancer already thrives online. It offers a challenge to the patriarchal structures within rhetorics of health and medicine, and it is also a site of knowledge construction. In this online space, there is the potential “of developing distinctive insights about systems of social relations in general in which their oppression is a feature” (Harding 9). Not merely a handholding support group, the online community is uniquely equipped to gather distinctive insights from several patients to represent the standpoint of many women. Knowledge is created in this space from the ethos of several thousand first-hand reports. As with other feminist endeavors, in this space, experience is valued:

Standpoint theory is an explicitly political as well as social epistemology. Its central and motivating insight is an inversion thesis: those who are subject to structures of domination that systematically marginalize and oppress them may, in fact, be epistemically privileged in some crucial respects. They may know different things, or know some things better than those who are comparatively privileged (socially, politically), by virtue of what they typically experience and how they understand their experience. (Wylie 339)

Feminist standpoint theory legitimizes the experience of patients. The large online community allows for a varied response, not one single standpoint, but several, that can answer critiques of standpoint theory that suggest it creates a false universalism. While more standpoints are not necessarily superior to an individual experience, the gathering of multiple experiences shares the knowledge of multiple experiences without a forceful consensus. Further, in this online community, the collaborative, conversant structure and the ethos granted to experience contributes to socially constructed knowledge formation and grants agency to the subjects. The cancer patients who make up this community are, in every other aspect of their care, subjects rather than knowledge-makers, and it is in the online community that they can claim authority. Within this feminist community, women challenge the patriarchal, epistemically privileged medical community to value and share the experience of patients.

For the purpose of this study, I will focus on one thread where a new community member, WorriedMama, prompted community members to tell the story of how they received their diagnosis. The response of the community exemplified the power of the online feminist challenge to medical paternalism and displayed the unique rhetorical possibilities of this collaborative space. This thread was a feminist response in several ways: community members were able to respond to medical paternalism enacted in the top-down policies of medical establishments; members pointed to the material conditions of their lives and how policy affected them, prompting a consideration of their feminist standpoint; the responses were poly-vocal, varied, and even contradictory without any pressure to come to consensus; all responses spoke with authority built from life experience; and the individual responses were gathered in one collaborative thread. Further, this site is feminist in that it offers a counter-discourse to the dominant narratives in mainstream mass-market publications and fundraising campaigns, i.e., the pinkification of breast cancer. This counter-discourse is protected in an anonymous forum that minimizes personal risk and allows patients to discuss sensitive issues. Certainly, the online site is not an ideal sisterhood of feminist empowerment. There are disagreements, personality clashes, and typical “flaming” episodes as in any online community; however, the online support community does seek to be a space that upholds feminist ideals of equity, representation, and collaboration, while enacting a patient-centered response to the patriarchal medical care system.

Online forums are affecting the doctor-patient relationship and should be explored further for their impact on the rhetorics of health and medicine. In “Writing Patient’s Wrongs: The Rhetoric and Reality of Information Age Medicine,” Karen Kopelson asserts, “The changing medical landscape of e-health remains underexplored by scholars in rhetoric and writing studies (including by those working in medical rhetoric), while the discursive reconfiguration of patienthood in the context of e-health has received less attention still” (356). Kopelson observes “the e-patient evolve from misinformed nuisance all the way to the patient who is a true medical ‘expert,’ fully empowered not only to ‘partner’ with doctors, but to manage many aspects of health care on her own” (356). While Kopelson considers the patient as a user of online information gathering, she complicates the bothersome image of the empowered patient armed with online research, and acknowledges, “the self-managing, expert e-patient is fast becoming a normative identity construct, which, like all normative identity-constructs, marginalizes alternative subjectivities and serves dominant interests—in this case, those of the medical power structure” (356-67). Kopelson notes, “What is at issue is that e-patients, by virtue of being e-patients, are being scripted as difficult, demanding, newly challenging; that

e-patients are being written into a position of (threatening) dominance, and that the ‘activating’ seed of their power is their internet-generated bundle or sheaf, which, we might note, is then consistently figured as a weapon” as they saunter into doctor’s offices armed with printed-out online research (366). We must, however, take this inquiry further than merely considering the effect of collecting Internet research. Yes, patients are empowered by information that they have gathered, but they have also found a space where their experience is valued and their standpoint is considered. When patients gather online, there is an inherent challenge to the dominant structure of medical paternalism.⁴

Despite mythical Hollywood dramatizations of patients wasting away, cancer is more accurately an expansion, an uncontrolled multiplication of abnormal cells. To even talk about cancer as one, singular thing is troublesome because as we learn more about cancer, we learn that it is a collection of idiosyncratic and individual diseases brought about by an unquantifiable number of hereditary and environmental factors that have some characteristics in common. Breast cancer alone is a topic much too expansive to be addressed by a single narrative. The multiplying numbers of breast cancer survivors coupled with the complexities of breast cancer contribute to the exigency of a community response. According to the American Cancer Society, one in eight women (12%) will develop invasive breast cancer in her lifetime (Key Statistics). In 2016 alone, there will be 246,660 new cases of invasive breast cancer, about 61,000 new cases of non-invasive breast cancer (carcinoma in situ), and 40,450 women will die from breast cancer (Key Statistics). If we add this year’s numbers to our existing survivors, “at this time there are more than 2.8 million breast cancer survivors in the United States” (Key Statistics). Further complicating these massive numbers are the many different types of breast cancer that alter everything from diagnosis and prognosis to treatment

4 I do not mean to establish a binary of patient/doctor, us/them. Many doctors work tirelessly to challenge the paternalistic traditions of medicine, but the motivations of doctors is outside the purview of this article. Here I am discussing the perceptions of patients and the consequences of being socialized to defer to the authority of the doctor. In my own experience, I had a wonderful oncologist, Dr. Nancy U. Lin, who answered my emails directly, and always had time for my questions.

plans.⁵ One narrative simply cannot de-mythicize or address all the concerns of these many, individual patients with diverse illnesses. One narrative simply doesn't represent the varied experiences of breast cancer patients. Just as I abandoned the bookstore in search of a community, thousands of women turn to the online breast cancer support community daily to find answers to their specific questions; to find others experiencing the same disease, treatment, or life conditions; and to tackle the mysteries and myths of cancer together. Consequently, what emerges when studying this space is not a pattern of response. In fact, the community is feminist in resisting predictable patterns of response as it allows for an appropriately poly-vocal and varied response to a complicated, mysterious, and deadly disease. One frequent indictment of online information is the simple notion that there is *too much* online. While patients can easily become overwhelmed by information, here the online community functions to organize and direct posts to people seeking the same sort of information. I believe that this poly-vocality, the allowance of differing, dissenting, voices and experiences to be gathered and searched to provide a community member with options for response is integral to making this community a feminist response to cancer. Rather than pushing toward consensus, the poly-vocal response inclusively represents many experiences and allows the patient the freedom to choose where to participate.

The online breast cancer support community is as complicated as the disease itself—an exponentially increasing number of community members creating posts that grow in number daily, providing not one response, but a plethora of responses to a multiplying number of inquiries. Together, the online community can function to de-mythicize cancer by sharing the first-hand, experiential knowledge of a large array of patients, and by answering the needs of many different patients. While this may seem overwhelming to an outsider, posing a specific question or finding a group in which you belong within the community is made navigable by the organizational structure provided. To use a feminist metaphor, the responses here are *gathered* for patients. This communication is entirely dissimilar to a one-sided web search that only returns an astronomical number of singular narratives. The gathering together of the poly-vocal response provides opportunity for understanding the complexities of breast cancer and its treatment. Sharing the experience of breast

5 Types of breast cancer include: Ductal Carcinoma In Situ (DCIS), Invasive Ductal Carcinoma, Triple Negative, Her 2 Positive, Estrogen Receptor Positive/Negative, Progesterone Receptor Positive/Negative, Inflammatory, Recurring, Metastatic, Medullary, Tubular, and Mucinous—and combinations of these types listed.

cancer is especially imperative because patients often feel that the topic is salacious, taboo, or potentially dangerous to their lives and careers.

Sontag cautions, "Since getting cancer can be a scandal that jeopardizes one's love life, one's chance of promotion, even one's job, patients who know what they have tend to be extremely prudish, if not outright secretive about their disease" (Sontag 8). When cancer is located in the breast, a sexualized area of the female body, communication can be risky in additional ways. Breast cancer patients often feel the inability to honestly discuss their illness even in professional medical settings. The online support community is a forum for joining together in secret to have open exchanges and minimize personal risk through anonymous screen names and thumbnail avatars.

Because secrecy is important to this community, I will not name it, but for the purposes of this article I will refer to the site I study as "Breast Cancer World" or "BCW." While there are many online support communities, I have limited my study to this one, large, international (although the vast majority of members are in the U.S.), and well-respected online breast cancer support site. BCW is divided into two large sections. One part of the site contains up-to-date, reliable information that is overseen by an advisory board of medical professionals. The community portion of the site contains a discussion board where the primary research of this study takes place. This discussion board currently has 80 forums where 174,717 members discuss 134,866 topics, but this number increases daily.⁶ Topics range from "tests and treatments" to "news and announcements." Moderators will often chime in on community posts in order to direct a member over to the information side of the site to clarify information or impede the spread of any confusing or erroneous advice. The administrators of the site establish the forums that create the structure of the discussion boards; however, within each forum, members start threads—discussions where the original post remains at the top of the page, and where responses can go on for hundreds of pages. Some threads become very popular. Some are typical reiterations of common issues (nearly every day someone posts that they are nervous about the outcome of tests), and some are routine (there are prayer threads where people post each day). Sometimes these threads are prompted by a development in the news, for example, a celebrity's handling of her/his cancer treatment, or a new advertising campaign that stirs controversy. There are "friend threads" where people have been posting so long that they know one another well, and new topics pop up every day as people come together to share the experience of cancer. Finally, there are transformative threads that challenge our notions of health-care and embody a feminist response to the treatment of breast cancer. The

6 These numbers reflect data gathered July 31, 2016.

thread I will discuss here was particularly transformative in that the patient struggled to understand the limited information she was given while awaiting her diagnosis, and was affirmed, joined, and informed by the responses of many. Her post was essentially a plea to help her de-mythicize the process of diagnosis.

For the purposes of this article, all posts are from the same thread begun in January 2012.⁷ In the “original post,” or “OP” of the thread, WorriedMama wanted to know if people were told of their malignant diagnosis by phone or in person at the doctor’s office.

I had a needle biopsy on Tuesday and the radiologist said that I will hear from my dr. Friday. This sounds great to me. I mean, if it's b9 [benign] they'd just tell me over the phone, right?

When my best friend was diagnosed with BC [breast cancer], the dr. called her once he had the results to make an appointment, then she had to wait for like a day or two. We were only 29 at the time and we thought that they probably always call you in for an appt., even if it's b9, so we were hopeful. Unfortunately, she had cancer. Since then, I thought that they probably only call you in if it's bad news and they can just give good news over the phone.

7 The University of New Hampshire Institutional Review Board deemed my study exempt. In addition to protecting the real life identities of my subjects, I have extended privacy protection in my study to include the privacy of the online identity, protecting and valuing that screen name as a holder of ethos and an extension of the community member. To do so, I have changed screen names and slightly altered verbiage in posts. I have been very careful not to change the intent, effect, or character of the posts. The changes are very slight, but I believe that in a community such as the one I am studying, where users can search archived posts and users have identities that mean a great deal to them, in which they have invested many hours to establish themselves as members of the community, this is an important step to take to ensure the privacy of my subjects—both real and virtual. In “Remix Cultures, Remix Methods” Reframing Qualitative Inquiry for Social Media Contexts,” Markham suggests that we should take a cue from Kincheloe’s “bricolage approach” to qualitative research by taking up the metaphor of the remix. Markham’s call to innovate methods of research makes room for this sort of “Adaptation and creative innovation [that] is sorely needed to study the complexity of digital life” (65).

Should I ask the office what their procedure is for giving results? I don't want to be a pest—especially since it's not a long wait.

So, I guess I'm just curious. How were you told the results?

-WorriedMama

WorriedMama's implicit question was "Is it a bad sign if the nurse calls me in for an appointment instead of giving the test results over the phone?" Or, more honestly reflecting the exigency of her post, her question was really "They called me in for an appointment. So, do I have cancer?" WorriedMama is acting on a myth. She questions if this myth is true: good news is delivered on the phone, but if they make the patient come in to the office it's bad news. At her invitation to share "How [you were] told your results," a narrative emerged comprised of many responses that basically addressed the question: "Where were you when you heard the news that would change your life?" There were 209 responses within two and a half months starting in January of 2012. The thread was briefly revived in October of that year. It has since been quiet, although similar threads asking about diagnosis procedures surface from time to time. Usually, questions from a "newbie," or a person new to the community, are factual—questions about side effects or managing life with cancer; however, this newbie asked community members to remember, recount, and reflect on their experiences as they first heard their cancer diagnosis. What emerged from the thread was a feminist response, based on the experiences of patients, in the form of the online, collaborative diagnosis narrative.⁸

8 The diagnosis of a life-threatening illness was added to the *Diagnostic and Statistical Manual of Mental Disorders* in 1994 (American Psychiatric Association). Certainly, all breast cancer patients don't consider their date of diagnosis traumatic. In fact, in "Cancer as a Psychological Trauma," James Coyne argues, "the casual assumption that cancer is traumatic has been used to turn patients' normal reactions to a diagnosis into a mental health issue, frighten persons who suffer from cancer, and promote bogus therapies" (1). Whether we categorize the moment of diagnosis as traumatic or not, the online community-written diagnosis narrative may function in the same way as retelling trauma therapies work toward lessening the isolating experiences of trauma.

Diagnosis Narrative as Genre

There have been many helpful and deeply meaningful breast cancer narratives⁹ and even graphic novels¹⁰ written for the public. In “Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance,” Judy Segal suggests that “breast cancer narratives have now become part of a dominant discourse, requiring a counterdiscourse,” and she cites the ways that they have “been coopted” by big business, industry, and pharmaceutical companies (6).¹¹ The counterdiscourse to these traditional, mass-market cancer narratives that Segal calls for already exists online. The genre of the online, collaborative patient diagnosis narrative challenges the dominant story by gathering together many voices within a community of peers to evaluate the traditionally dominant culture, the medical paternalism, of the healthcare industry.¹² While several breast cancer narratives briefly discuss the moment of diagnosis, the larger emphasis of these narratives and graphic novels is usually placed on treatment and the journey toward recovery, remission, or death. The online community-written diagnosis narrative focuses on one crucial and shared moment in the process of the cancer journey—the early, terrifying moments of diagnosis that all patients share.

9 *Breast Cancer Narratives: Betty Rollin’s First, You Cry; Joyce Wadler’s My Breast; Audre Lorde’s The Cancer Journals; Barbara Ehrenreich’s Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America; Tania Katan’s My One-night Stand With Cancer*

10 *Breast Cancer Graphic Novels: Marisa Acocella Marchetto’s Cancer Vixen; Miriam Engelberg’s Cancer Made me a Shallower Person: A Memoir in Comics*

11 See also Segal’s “Cancer Experience and its Narration an Accidental Study.”

12 In *Genre Analysis: English in Academic and Research Settings*, John M. Swales states that “genres are communicative vehicles for the achievement of goals” (Swales 46). In “Genre as Social Action,” Carolyn Miller explains “a rhetorically sound definition of genre must be centered not on the substance or the form of discourse but on the action it is used to accomplish” (151). Although there are shared features of the individual responses within this genre, I resist pointing to the similarities of posts because it is the diversity of responses that makes this a unique genre where the shared actions of working through the difficult, perhaps traumatic experience of diagnosis defines this genre. The online setting makes possible the collaboration of poly-vocal responses that need not lead toward consensus to create a new diagnosis narrative—the online collaboratively written diagnosis narrative.

In “Genres in the Internet: Innovation, Evolution, and Genre Theory,” Janet Giltrow and Dieter Stein push scholars to consider the effect of the online space on genres that may already exist in print forms. “The Internet enables a new communication setting which reconfigures the conditions to which pragmatic features of language respond,” essentially changing the genre (Giltrow 9). Giltrow and Stein go on to name a few of the features of this online communication:

The main components of this new communication setting are the vast and variable range, new pull and push mechanisms, new distance-synchronic forms of communication, new combinations of N-to-N—the number of people speaking and the number of people receiving the communication—and the high speed as well as the archiving of interaction. (9)

It is precisely these features, only enabled in an online community, that make the online, collaborative diagnosis narrative possible.

The patient diagnosis narrative is the first-person account of hearing the news of one’s diagnosis for the first time.¹³ Key features of this genre in the online breast cancer community include a thick description of the location where one heard her diagnosis, a recounting of the conversation, an exploration of one’s emotions at the time, and finally, perhaps most significantly, an assessment of the appropriateness of the exchange between patient and

13 Rita Charon, Professor of Clinical Medicine and Director of the Program in Narrative Medicine at the Columbia University College of Physicians and Surgeons, coined the phrase “narrative medicine” as “a unifying designation to signify a clinical practice informed by the theory and practice of reading, writing, telling, and receiving of stories” (Charon viii). She describes Narrative Medicine as “A clinical cousin of literature-and-medicine and a literary cousin of relationship-centered care,” and describes the outcome as an opportunity for health care professionals to understand the patient’s perspective more thoroughly, and to explore their own perspective as doctors (Charon vii). Charon claims that: “what medicine lacks today—in singularity, humility, accountability, empathy—can, in part, be provided through intensive narrative training. Literary studies and narrative theory, on the other hand, seek practical ways to transduce their conceptual knowledge into palpable influence in the world, and a connection with health care can do that” (Charon viii). Although Narrative Medicine provides a “practical” application of literary studies and narrative theory to the world, the online breast cancer support community is already a site of narrative theory in practice, where this theory of allowing for “singularity, humility, accountability, and empathy” is already in action at BCW.

doctor according to the needs of the patient within a dynamic, collaborative thread. The telling of one's narrative helps to solidify the memories of readers who then become authors and reflexive participants in the narrative construction. In an asynchronous space, where members do not have to be online at the same time to interact, the reflection back to one moment, the moment of initial diagnosis, while different for each member, is a unifying construct.

In the OP that began the thread of diagnosis narratives, WorriedMama is new to the site, but she already uses the language of the community in the shortcut "b9" for benign, meaning not malignant. The exigence for her post is that she doesn't know how to interact with her doctor, and she is not empowered to ask her doctor for an answer to her simple questions due to medical paternalism that has left her scared, confused, and unsure of proper protocol. She worries that simply asking the office about their policy for sharing diagnoses will cause them to label her "a pest," and that concern leads her to the feminist online community where her post is safe in its anonymity, heard, and validated in its responses. WorriedMama is silenced by medical paternalism and top-down policy, and so she turns to this feminist community for guidance. As WorriedMama waits for her testing results, she is unaware of the parameters of her appropriate behavior as a patient, despite the shared experience of her friend's diagnosis. And though this issue was important enough to send her to the online community, she still qualifies her question with a dismissive "So, I guess, I'm just curious." Like many female breast cancer patients before her, she is silenced by her role as patient in the hierarchical doctor-patient relationship. The fact that she feels that she can't even ask her doctor's office about their policy for fear that she will be labeled a "pest," and that could be harmful to her care, should be of great concern and is what led her to this collaborative community. WorriedMama perceives that she can't ask her doctor a question, and in her fear and anxiety as she waits for her diagnosis she goes online. In turning to the community of women online who have shared the experience of diagnosis, her voice will be heard and her concerns will be validated and shared by others.

Ambience and Back Stage Patient Discourse

I heard on the phone. I will never forget how I felt like I had been kicked in the stomach. I just KNEW something was wrong and had told the doctors of my chest pain for nearly two years, but neither the oncologist nor the plastic surgeon believed me because my cancer was sooo small and node negative. Finally, I convinced them to do a bone scan because it would "make me happy," and a few days later, as I talked to a friend on the phone the operator broke in to say I had an emergency call. It

was the doctor calling to say that she was sorry, but the breast cancer is back and it's metastasized to the bone.

Then I went in for a CT scan and it was also in my lung and liver. I called her to get the results of that test and when she got on the phone she asked me if I was sure that I wanted her to tell me this news while I was at work. Well, since you put it that way, I think you should. I got a new oncologist after that.

-GraceCee

One key feature of the online diagnosis narrative is the evaluation of the diagnosis interaction from the standpoint of the patient. Contributors to this discussion thread always spend some time reflecting on what would be the best way, for them in their particular situation and in light of their material needs, to be given the disturbing news of diagnosis. The gathering together of these poly-vocal responses allows for several standpoints to be considered. Preferences varied greatly despite the fact that the policies regarding the dissemination of diagnostic information were determined almost exclusively according to the doctor's preference without the input of patients. The medical paternalism of these top-down policies is challenged by this poly-vocal response that resists consensus. By considering several standpoints of patients receiving their breast cancer diagnoses, we de-mythicize the unknown possibilities of this interaction.

A definitive diagnosis can only happen after a biopsy, and so doctors must be cautious in their word choice leading up to that diagnosis. While experience and all signs may lead a doctor to believe that the patient has cancer, a doctor will take care not say the words "you have cancer," until test results are received and the diagnosis is confirmed by the pathology. But patients listen very carefully to the clues doctors give. Obviously, by asking GraceCee if she was sure she wanted to hear her results while she was at work the doctor already told the patient that the news was not good. GraceCee felt repeatedly unheard and dismissed by the medical community. Her post doesn't complain about the doctor, but her negative assessment is very clear in the mocking tone she uses when she adds extra o's to "sooo small," the snarky "Well, since you put it that way," and her ending comment that she "got a new oncologist after that." Many patients on the thread felt the need to look for a new doctor based on the manner in which they were told of their diagnosis. In the doctor-patient relationship that hasn't fostered democratic exchange, the patient uses their only recourse—to simply not return to that doctor and establish the next doctor-patient relationship with more input from the patient; however, one cannot choose a new doctor until one is diagnosed and knows what sort of doctor she needs. Sharing this path to empowerment with other

community members can, in turn, empower them to choose a health care practitioner who does not dismiss their concerns. The moment of diagnosis is, necessarily, early on in one's journey as a patient, and so the learning curve is steep for patients. Some feel empowered to get a new doctor after those first interactions about diagnosis, but they would not have known to ask for that care before this experience.

Just as GraceCee was "told" by clues in the doctor's call before she was explicitly told her diagnosis, many women expressed that they were sure of their diagnosis before anyone said the words out loud. Perhaps the overwhelming number of breast cancer diagnoses today causes doctors to be less cautious as they interact with patients; perhaps a litigious society has led to an understandable fear of doctors saying anything that could be misinterpreted; perhaps patients are much more savvy about interpreting the motivations of doctors as they have more information from peer-to-peer healthcare sites, or perhaps patients are simply well attuned to read the signs, or as one woman called it "a number of small 'tells,'" that a cancer diagnosis was imminent in order for the patient to have time to prepare to hear the news. In *Ambient Rhetoric: The Attunements of Rhetorical Being*, Thomas Rickert suggests that "We are entering an age of ambience, one in which boundaries between subject and object, human and nonhuman, and information and matter dissolve" (1). As we navigate this age, "wakefulness to ambience is not a subjective achievement but rather an ambient occurrence: an attunement" (Rickert 8). The desire for information, and the simultaneous fear of that information, awakens that attunement to one's environment as patients await a cancer diagnosis. Rickert explains that we must "expand the concept of attention beyond that which is limited to the subjective, intentional, or merely cognitive; attention would thereby come to include the materiality of our ambient environs, our affective comportments, the impact of that which escapes conscious notice, and the stumbling block presented by the finitude of knowledge when facing the plenitude of the world and its objects" (xi). One patient's heightened attunement caused her to be "told" her diagnosis by the sound of a bag on her door:

As I sat in the exam room with my hubby I heard the MD whisper something, and then I heard someone putting a bag of stuff on the other side of the door. I knew then they were going to give me a bag of information that I would only need if I had cancer. The wait between hearing that bag put on the door and the MD finally coming in was excruciatingly painful. I just wanted to back up and not open the door.

-CityChica

This doctor's office generously gathered some information and some sort of free cancer "swag" as a kindness to the newly diagnosed cancer patient. Perhaps the bag included a binder or a pamphlet like the one I searched for the day of my diagnosis. In these initial moments of diagnosis a patient is attuned and desperate for any information, so CityChica read all the "available means of persuasion" as Aristotle defined rhetoric. The sound of the bag on the door was, essentially, the way she heard her diagnosis, and as we can see by her very strong word choice, she found it "excruciatingly painful." In the attempt to do something kind for the patient, the medical establishment let CityChica down. CityChica puts the reader in her shoes and lets us experience her standpoint. We are with her as she hears the bag, and we share her thoughts when she rightly guesses why there would be a bag on the door, and her very strong word choice of "excruciatingly painful" is so heartbreakingly honest that we sympathize with her as we share that suspended moment before the door opens and the bad news is delivered. Where she was once silenced, she found a space in the online community to put her experience into words. The danger of medical paternalism is that the medical establishment doesn't consider the standpoint of the patient when establishing office policy. CityChica's doctor's office provided the "swag bag" as a kindness, but no one in the office considered the standpoint of the patient trapped behind the door. Both GraceCee and CityChica realized that the doctors were trying to be kind, but both patients described the experience as painful.

In "Discourse Methods and Critical Practice in Professional Communication: The Front-Stage and Back Stage Discourse of Prognosis and Medicine," Ellen Barton uses Erving Goffman's theatrical terminology to analyze the "front-stage" and "back-stage discourse" of physicians' prognosis discussions with patients. Barton follows oncology physicians through their presentations of prognoses to patients with cancer, their "front-stage discourse," and then engages with the physicians in their "back-stage discourse," or when "on the back stage in the hallway or clinical work area, these same professionals talk as co-workers, coconstructing an insider discourse of medicine that covers a variety of medical and nonmedical topics" (Barton 71). In other words, the back-stage discourse is the uncensored quip, the truth-telling, bluntly-stated assessments not appropriate for patients, but perhaps most sincerely expressed. Ultimately, Barton concludes that despite the difficulty of physicians who are genuinely torn between truthfully informing a patient about his or her illness and destroying any hope that could make a difference in a patient's quality of life and potentially even impact their prognosis, the back-stage discourse may have important implications for front-stage practice. "If back-stage discourse expresses experience in the absence of false hope," Barton writes, "such realism could (and perhaps should) recursively enter the front-stage discourse of

prognosis" (106). Barton suggests here that we rethink medical paternalism. In both GraceCee and CityChica, we see patients who, through their attunement to ambient rhetoric, overhear that "back stage discourse" of physicians. While doctors' back-stage discourse occurs in the hallways, the back-stage discourse of patients is the online support community. Just as Barton uncovered a space where physicians were able to speak with greater honesty, the online community provides the un surveilled space where patients can engage in the same sort of uncensored truth-telling, and more strikingly, the patient standpoint can be given voice.

Dissensus and Material Conditions

Consensus is not a goal of the online discussion board. And so, the online community is feminist in that it allows for varied and even opposing points of view to be considered without any pressure to come to consensus. The feminist, poly-vocal response challenges the top-down response of medical paternalism. The online community allows for several voices to be heard and considered.

I told them up front that I did not want to be told the results on the phone. I live by myself. I brought my two sisters with me for the results. I needed their support.

-EveinTX

EveinTX claimed the power to direct her care. While many members in the discussion reflect on the experience of their diagnosis only in retrospect, EveinTX reports that she anticipated her needs as a patient, and advocated for what she needed. Even at this early stage in her breast cancer treatment, she told the office how she wanted to hear the results. Perhaps her desires were easy to fulfill because they happened to align with the office policy (i.e., being told results in person), but regardless, EveinTX's impression was that she got what she asked for in her treatment. It is less common in the thread, but there are some patients who, right from the outset, feel empowered to dictate the terms of their treatment. And we can see that EveinTX shares her experience without prescribing action for others. Like posts before her, she recounts how she was told the news, but she also shares the motivation for that decision. Her statement, "I needed their support," served not only to explain her actions, but to clue in readers that maybe they might also need the support of others and may want to plan before the diagnosis meeting to ensure that kind of support. EveinTX certainly has a strong point of view, but she simply shares

her course of action and motivation. As a feminist response, she gives this cue not as a directive statement, but rather as an explanation that the reader can then consider and choose to follow or not.

While it seemed that the overwhelming preference of doctors was to call patients in to give them bad news in person—perhaps as a perceived display of kindness or a requisite performance of compassion—many women simply did not have the time for the luxury of a private appointment with a doctor. Unlike a traditional single-authored narrative, the online community allows for response, and often that response can be in direct contrast to the previous post. Many women worked to balance their own needs for emotional support with the material conditions of their lives. This community allows patients to voice their individual preferences that challenge blanket policies made by doctors. SurvivorinPink responded to EvieinTx's post, offering a new patient standpoint:

Why should I take more time off work for an appointment, pay another copay, and sit in an exam room just to hear yes or no?

-SurvivorinPink

It is real life, material concerns such as these that are often ignored when doctors have a blanket policy for delivering results and diagnoses. Once again, the patient gives voice to the conditions of life that may go unconsidered by top-down policies. The cost of cancer care can be astronomical. Even those lucky enough to have good health care will see a large increase in their health-related costs while undergoing treatment. For a doctor to assume that it is economically feasible for women to come in for another appointment just to discuss a diagnosis, even if that doctor's motive is to provide emotional support, is not enacting a feminist model of care, one that considers the material conditions of one's life. Despite the best intentions of her doctor, SurvivorinPink has more basic needs to consider—the very real economic cost of taking off work and paying for a visit. Her post inspired others to contribute to the thread in agreement.

As a single, working mom, I'm thankful for anything I can do over the phone so I don't have to miss work unless it's absolutely necessary. Plus, I'm a very private person and prefer to deal with things on my own at first, so having a day to process my diagnosis before meeting the surgeon was perfect for me.

-GeorgiaPeach

GeorgiaPeach expresses both economic concerns and an emotional concern. Her post agrees with SurvivorinPink. GeorgiaPeach also has work to consider

when making appointments, but she also responds to EvieinTx by offering an alternative emotional need. Where EvieinTx needed the support of her sisters, GeorgiaPeach needs time to process. No post disagrees with another here or negates the previous contribution; they simply offer alternatives based on each patient's needs—consideration lacking when policy is written in a top-down fashion. In gathering the voices of many patients, the online, collaborative diagnosis narrative represents an inclusive and diverse portrait of patient needs.

The resulting collaborative narrative in the online setting is a shared narrative, a communally composed story where one post influences another, a woven fabric of experience where one post relies on the next, not merely a collection. A detail in one post inspires someone to remember her own details. One's impression of the doctor's motivations for proceeding the way she/he does prompts another community member to defend or join in on a criticism. The online space, the context of this communicative writing act, influences the construction of the narratives in collaborative ways that writing alone cannot. While the details may change, all the participants and nearly all of the audience members share the community and the experience of diagnosis, and so a new narrative genre emerges, and a unique form of collaborative narrative construction is evident. Rather than a unified narrative, the knowledge in this space is created by the whole community in an inquiry-based approach, one that reflects feminist values of questioning, complicating, and sharing viewpoints rather than a paternalistic narrative of questions and answers and top-down authority.

In addition to the material conditions of women, one post brought to light the added challenge of engaging with the medical community with a disability. SilverLining, a hearing-impaired community member, clearly illustrated the importance of considering the individual standpoints of patients:

My bad-delivery-of-news story is after the magnified views mammogram, I waited almost a month to hear results. I had asked them to send results to my family physician because I am deaf and they couldn't call with results or to make appointment. Finally, I got aggravated with waiting and had my husband call the hospital (he can hear a bit, but prefers to make rather than receive calls). It turns out that the hospital, having found that I had no phone number on file, had taken it upon themselves to ignore the annotation on the chart to call the family doctor, deaf, etc. and decided to search through 15-20 year old directories and found the telephone number of my parents' house where I had lived for part of grad school, and were trying to call them to recall me for an appointment. Now, they are both elderly and my father is unwell since his younger brother died of cancer. I had been going out of my way to keep them out of the picture and the hospital clumsily almost outs

me. Fortunately I think they thought it was just a fundraising call from the hospital foundation and never mentioned it. Worse, having been unable to reach anyone that way, the hospital was just sitting on the results. Idiots.

-SilverLining

SilverLining shared her “bad-delivery-of-the-news story” in a way that indicated that it was just one of the many challenges she faced in her journey as a deaf cancer patient. Once again, the benefit gathering many patient responses in one community can help us all reach a feminist inclusivity of representation that resists consensus and considers a wide range of patient needs.

Weaving the Threads of a Kairotic Response

Do you think I'm nuts for taking so much time talking about things here but no time at all researching breast cancer? It seems a lot of you think I should prepare for the worst, but keep hoping for the best, and that's how I usually do things. But I love to research generally, and I can't handle even looking up terms. I'm not sure if I'm trying not to tempt fate or if I just don't want to waste my time when I may be alright.

-WorriedMama

There will be time to ask your doc all the questions you come up with after you have a diagnosis. I was too nervous to research. So, you don't have to! I didn't. Your own particular diagnosis will bring up a million questions to drive you crazy, so don't take on all the unknown possibilities that won't have anything to do with you. I think you're doing great. Good luck!

-SandyTeacher

Thanks, SandyTeacher. I am feeling better. Talking with all the people on these threads has been so helpful.

-WorriedMama

The facts can be frustrating, but I felt better after I researched. I just tried to only research where I was in my treatment and not get too far ahead. So, I just finished radiation, and I'm about to have my yearly gynecology appt. So, right now I'm looking up preventative ovary removal. It came up before, but now that I'm going to see my doctor, I'm taking the time to research it.

Take care!

-TruthTeller

That is great advice. Of course you'll want to research a lot after you find out your diagnosis, so for now just research where you are.

-SandyTeacher

Thanks, Sandy – it has been helpful for me so far. I was really happy that I found a step-by-step description of a sentinel node biopsy online. I watched it right before my procedure and it was so helpful to know what they were going to do instead of imagining the worst.

-TruthTeller

WorriedMama admits that she is using the community rather than conducting “research” in anticipation of her diagnosis, and even acknowledges that she is perhaps seeking advice from an inappropriate source. She even asks if she is “nuts” for seeking out community knowledge rather than conducting research. Left on her own to de-mythicize cancer, she wants a response—or several—rather than a static article. She asks for peers to respond to her concern, not her medical condition. This space answers her call for information based in experience. The response is terrific advice from two other community members that have shared the experience of the start of a cancer journey—advice that suggests strategies for managing the overwhelming amount of information available from people who have had this experience themselves. Once again, even though the responses seem contradictory (SandyTeacher says to wait to research and TruthTeller suggests researching in appropriate stages), the community members collaborate and agree to revise the advice showing the benefit of this poly-vocal response. And although SandyTeacher’s response can sound directive in her response that WorriedMama should not “take on all the unknown possibilities that won’t have anything to do with [her],” SandyTeacher offers not researching as an option, not a prescription. Further, SandyTeacher offers the option not to research because that was what worked for her in her experience as a cancer patient. In *Kaironomia: On the Will-to-Invent*, Eric Charles White expands on the implications of the term *kairos*, beyond its common definition of “the opportune moment,” by tracing the origin of the word *kairos*. One possible origin of the term *kairos* comes from weaving, traditionally a woman’s art, when the weaver pulls the yarn through a gap in the cloth’s warp. In *Weaving the Word*, Kruger traces the anthropological history of weaving in which it was largely the women’s role to produce cloth, and connects that practice to literate practice where “women took part in the first textual practices, recording their society’s stories, myths, and sacred beliefs in the symbols woven or embroidered on their textiles. The scene they conveyed constituted society’s first texts” (Kruger *Weaving the Word* 22). Thus, the weaving process has its roots in the very first literate acts by women. The online environment has, in large ways,

become a new community, and the literate practices of women have moved to this space and have been transformed by it.

The language of weaving is already present online in the discussion board where discussions are called “threads.”¹⁴ This metaphor also works so well here because the gap that opens in the cloth is literally nothing without the perpendicular threads of warp and weft coming together. In this predominantly female-populated space online, opposing voices counter the dominant cancer narratives and even counter one another as they collaborate not toward consensus, but toward a woven cloth of opposing, yet complementary threads of narrative. The online discussion thread does not stand alone, but rather it is woven into a collaborative narrative. The diagnosis narrative is kairotic in that it is a genre that is rooted in time, the first moments of diagnosis, but in addition to responding to a moment in time, the diagnosis narrative also creates a kairotic moment in the actual moment of the community response online. As women come together to share these memories, they create a kairotic response to the original post. Just as the posts are gathered, the patients themselves gather in sharing this experience. Further, Berkenkotter and Huckin connect the concept of genre to a “highly developed sense of timing” where the writer must consider “At this moment, what are the compelling issues, questions and problems with which knowledgeable peers are concerned?” (3). Although Berkenkotter and Huckin discuss the academic writer, the genre of the online diagnosis narrative answers this kairotic moment where online communication, immediate access to information, and complicated disease come together.

Sharing the Opportune Moment

The message boards online are asynchronous, so community members do not have to be online at the same time to engage one another in a conversation or thread. These threads are all saved, and so from time to time someone searching the site might “revive” an older thread. There are even some threads that remain active long after the member who started the thread has left the community. In essence, what remains online is an archive of these conversations—a living archive that can be added to as time goes on, and so time in this space is a complicated notion. Medical advancements and changes in treatments can make older messages irrelevant and even incorrect, necessitating that time become an important marker in the online community

14 Lora Arduser also uses this metaphor in her *Journal of Technical Writing and Communication* article “Warp and Weft: Weaving the Discussion Threads of an Online Community” that studies the online Tu Diabetes site.

when advice is shared and accuracy is valued. Members who have posted on the boards about the miraculous successes of their treatment protocols have gone on to recur. Women who came to the site trembling with fear and posting about their likely upcoming cancer diagnosis have heard benign results and left the community. Treatments once considered groundbreaking can become outdated, and innovations can render what had seemed unerringly bleak statistics untrue and unnecessarily frightening, but all of those posts remain in the archive. Like any archive, the online space is a stored record of these communications, but at the same time it is a 24-hour, awake, active, global community.

Community members often comment on the late hour as they post on the discussion board. While I do not have data to support the thesis that activity increases during the night when people can't make phone calls or visit "IRL" (In Real Life) friends, a simple search of one site yielded over 60,000 posts containing the word "alone." The stress of a cancer diagnosis can undoubtedly keep one up at night, and chemotherapy can also cause insomnia in patients. But even in the quiet hours of darkness, the "Active Topics" board is awake and refreshes with every new post on the site. Unlike in-person support communities, someone is always awake and available online. In an online city that never sleeps, but that holds and records every moment shared, time is created by the community and becomes crucial to determining the validity of information and experience.

Many "friends," or more significant relationships in the online community, are made when members share an experience in time. Threads are often created for people starting chemo in a particular month, or having mastectomies in a certain month, and these threads remain active for a long time as the participants can compare and share their experiences as they go through them together in the same time frame. The moment of diagnosis is perhaps the most consequential and *kairotic* moment of exigency in the rhetoric of this space. It is also a mutable time. While the moment of reflection may not be consistent—some stories were told about the present week, and some stories went back decades—the moment of the subject of the stories is consistent. The *kairos* of a written text is necessarily different from the passing moment of oral discourse:

No writer can account in advance for every such need [as in oral discourse where an evaluation of what the moment requires can be assessed], so 'occasion' for written texts must refer to the situation initially eliciting the writing, whereas *kairos* itself will pertain more to the harmonious and appropriate fashioning of a suitable text. (Sloane 530)

The sharing of that passing instance of life-change is the “occasion” for the woven, kairotic response. When a patient is diagnosed, it is an isolating experience. What is shared, at the moment of diagnosis, is the single most profound aspect of the self. Suddenly, other identities like “wife,” “mother,” “professor,” “writer,” are all pushed to the side as one discovers that the most profound thing about them is no longer shared with family and friends, but with every other woman participating in the virtual breast cancer community. In *Doctors’ Stories: The Narrative Structure of Medical Knowledge*, Kathryn Montgomery Hunter describes this loss of the self: “The act of becoming a ‘patient’ is itself a first step in assuming a nonpersonal, medicalized identity. The translation of the patient’s story into the medical discourse involves the substitution of the case for the person: the patient is impersonalized, represented in the medical arena by an objectifying narrative” (Hunter 134). BCW provides a space to de-mythicize cancer within a community of peers, mitigating the isolating experience of disease.

Further, the time created in the sharing of these contributions to the thread, the individual threads that weave together to make *this* narrative, create a kairotic moment that allows for the empowerment of the patient and the breast cancer community as a whole. This reconception of time as something fluid yet shared can only happen in this online community. Whether a patient’s diagnosis was heard the day before they posted or ten years prior, they were able to share that moment in this online community. And it remains to be shared with others as they encounter the same experience.

Peer-to-Peer Feminist Response

KatieM - Congrats on your wedding. I just wanted to clarify what was posted above. Chemo can cause menopause, but Tamoxifen doesn't. Tamoxifen can give some of the same symptoms—hot flashes, infrequent periods—but it doesn't make you infertile. Tamoxifen does cause birth defects though, so you can't safely get pregnant on it. Lots of women take it for a couple of years, have a child, and go back on it. I was not menopausal after chemo. Some chemo drugs make it more likely than others, but there are other factors too like the dosage and your age. I did IVF and froze 16 embryos before I started chemo just in case. I'm so glad that I did, even though I was still fertile after.

Most importantly, remember that the overwhelming majority of biopsies come back negative! Younger women, especially, have dense breasts and lots of hormonal changes. They are very cautious if you have a family history. Good luck and remember that the odds are you are completely fine!

-Dreamer864

Dreamer864, is quite knowledgeable about breast cancer. She was a seasoned contributor to the site, and her response inches toward medical advice in some sense as she clarifies the side effects of the popular drug, Tamoxifen; however, her advice is firmly rooted in her own experience going through chemotherapy as a young woman whose fertility is a major concern. Much like other activities that are viewed as extracurricular and unimportant, the online breast cancer support community has been dismissed as an amateur response to the search for medical advice and a possibly dangerous space where unreliable information can easily be spread.

Just as Kruger, in his study of weaving, argues for the legitimacy of and respect for the tasks of female experience, I argue that the online breast cancer support community is a space that we must reclaim as a legitimate contribution to rhetorics of health and medicine:¹⁵

I suspect, however, that no matter how determined scholars may be to engraft feminist studies onto the root of historical and cultural studies, no real change in the view of women in history will occur until modern society changes its perception of those tasks that make up this female experience, tasks like weaving and sewing, cooking and childbearing—and begins to esteem them. Without respect for this work, the history of female experience will always be considered less valuable than its historical male counterpart in male experience. (Kruger 22-23)

The online community is a legitimate part of women's literate practice and a genuine feminist contribution to rhetorics of health and medicine.

Work in rhetorics of health and medicine has contributed to our understanding of common genres of writing seen in medical settings or the professional discourses of health and medicine.¹⁶ It is my hope that this analysis adds to this work by moving to the margins of healthcare—in studying people outside the medical community yet completely immersed in it. As Ellen Barton states in her 2005 introduction to the special issue of the *Journal of Business and Technical Communication* on the discourses of medicine, “Attending to the organization of the language of medicine into genres—with their powerful effects on the formative and normative discourses of the profession—is an

15 Blake, Segal and Keranen ask scholars to adopt the term “rhetorics of health and medicine” in order to “signal a broad array of health publics, their *nomoi*, and their discursive practices, some of which only partially intersect with medical institutions” (1-2).

16 See Wald, et al. “Untangling the Web—The Impact of Internet Use on Health Care and the Physician-Patient Relationship.”

important interdisciplinary contribution our field can make" (248). In "From the Frontiers of IMRAD: Nontraditional Medical Research in Two Cancer Journals," Michael Zerbe seeks out "nontraditional science articles," that he defines as "those that focus on issues other than the cancer and that often consider human beings as a whole, rather than solely a disease that happens to be carried by a human being, as their primary object of study" (207). In his endnote to that statement, he acknowledges, "The vast majority of these physicians, of course, care deeply about their patients. The existence of this relationship, however, does not change the fact that the voices of patients are typically not heard in traditional science research" (Zerbe 219). Zerbe attributes this silence to the need for the quantification of scientific research methods: "Because a single patient is almost always just one of many patients being treated (statistical significance is much easier to achieve with large sample sizes), she or he is characterized primarily as a carrier of cancer and little more" (207). The patient voice is also seldom heard in research in rhetorics of health and medicine because attention is mainly paid to genres of writing within the professional disciplines that exclude patient voices. By contrast, the online site serves to gather together individual voices to create a statistically significant corpus of patient responses. By considering the voice of patients and honoring the ethos of patients' experience, we can enact feminist values of representation. In essence, the online breast cancer support community is a place of feminist standpoint praxis.

Further, although my research casts a spotlight on the rhetorical acts of a previously under-valued online women's community, this project participates in a legacy of extending the feminist lens by using a feminist methodology to research and interrogate this site of rhetorical practice, participating in "feminist rhetorical scholarship [that is] now moving far beyond the rescue, recovery, and (re) inscription of a diversity of women participants" (Kirsch and Royster 642). As a widespread, overwhelmingly female disease, and one that is centered on a sexualized portion of the female anatomy, breast cancer has been a context for previous challenges to the patriarchal medical community. For example, in *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in the Twentieth-Century*, Barron H. Lerner highlights the activist history of breast cancer when the default treatment for breast cancer was the radical mastectomy, taking far more tissue than was necessary without regard for a female patient's psychological well-being. The "Radical mastectomy, performed mostly by male surgeons on female patients, had become a touchstone for dissatisfaction with a patriarchal and authoritarian medical system," leading to

changes in surgical protocols (Lerner 4)¹⁷. The nearly ubiquitous pink ribbon campaigns, while seen by some as a falsely feminine and precious way to describe a deadly disease and a narrative put forth by the breast cancer industry to politicize breast cancer in the U.S., began as survivor-created responses to a system in which the patient had no voice. These movements have transformed the experience of patients from solitary suffering to the opportunity for community, survivorship, and celebration, but they have become the language of the breast cancer industry rather than the patient. Many of today's breast cancer patients resist the pinkification of this deadly disease. To avoid being coopted by the "business" of breast cancer, patients are voicing their experiences of illness online.

Lest we think that all the posts were indictments of the medical community, a great number of contributors to the thread noted an appreciation for the difficult position of doctors. Although it's true that most doctors mentioned in the thread dictated the terms of the doctor-patient relationship, many posts expressed empathy for the doctors who had to deliver devastating news to patients. SurvivorinPink posted: "My oncologist called me on a Friday, and was very compassionate and professional about it, but got right to the point." Prayers 2011 had nothing but praise for her doctor:

When she did call, she was awesome. She wanted to know how I was doing after the biopsies, and then said, I'm so sorry. It's cancer.

17 See *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* by Barron H. Lerner, M.D. for "a history of breast cancer diagnosis and treatment in twentieth-century America," with a focus "on the years from 1945 to 1980" (4). See also Maureen Hogan Casamayou's *The Politics of Breast Cancer* for an account of the National Breast Cancer Coalition's activist successes gaining "extensive media coverage as well as both attention and action from Congress and the White House in the period between 1990 and 1993" (ix). These histories cast a spotlight on the tradition of women's healthcare initiatives in the treatment of breast cancer as successful challenges to the patriarchal system of medicine. For more on the public narratives of breast cancer, see also Samantha King's *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy*, Ulrike Boehmer's *The Personal and the Political: Women's Activism in Response to the Breast Cancer and AIDS Epidemics*, Gayle A. Sulik's *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health*, Lisa Keränen's *Scientific Characters: Rhetoric, Politics, and Trust in Breast Cancer Research*, and Mary K. DeShazer's *Mammographies: The Cultural Discourses of Breast Cancer Narratives*.

She then gave me the good information (that it was small, slow-growing, caught early), and she paused every few minutes to ask how I was doing, how I was processing all of this information, and if I needed her to repeat anything.

We really did have a wonderful conversation—about much more than just my diagnosis. I was shocked, and I cried when I hung up the phone, but I was glad this doctor was the one to tell me.

-Prayers2011

These complimentary posts display the feminist impulses of the community. In a truly generous rhetorical move, even while challenging the power dynamic, they consider the feelings of the empowered.

Implications and Conclusions

This is an intervention. A message from that space in the margin that is a site of creativity and power, that inclusive space where we recover ourselves, where we move in solidarity to erase the category colonized/colonizer. Marginality as site of resistance. Enter that space. Let us meet there. Enter that space. We greet you as liberators.

-bell hooks "Marginality as Site of Resistance" 343

In *Feminist Theory: From Margin to Center*, bell hooks said "To be in the margin is to be part of the whole but outside the main body" (xvi). In "Choosing the Margin as a Space of Radical Openness" she expanded on this concept to show the transformative power of the margin: "that it is also the site of radical possibility a space of resistance. It was this marginality that [she] was naming as a central location for the production of a counter-hegemonic discourse that is not just found in words but in habits of being and the way one lives" (206). Medical patients are the often-powerless subjects of the study of their own bodies, and given that the overwhelming majority of breast cancer patients are women, I believe that viewing this space as a marginal site where the silenced

find agency and power is productive.¹⁸ In cancer vernacular specifically, the term “margin” resonates deeply. In order to give a patient the best prognosis, the surgeon who removes a tumor or area of malignancy must achieve “clear margins.” To hear that phrase in a post-surgical report means that the surgeon has removed enough of the surrounding tissue to improve the patient’s prognosis and reduce the likelihood of recurrence and progression. But patients also often remain on the margins of their own care throughout cancer treatment. Right from the start of an illness, the doctor decides the process by which the patient hears the diagnosis without considering the standpoint of the patient. Even with recent attention paid to collaboration in medical care, patients are often simply told doctors’ policies without the opportunity to participate in and direct their own care. But the gathered posts of the online community move patients from the margins of their care to the center of the community response. The structure provided gathers together many different responses, allowing for many standpoints to be considered by the group.

First and foremost, studying the rhetoric of the nearly exclusively female, online community of breast cancer patients contributes to our examination of feminist rhetorical theory in practice. Women come together on this site to share the ethos of their experience, and in doing so create knowledge, support one another, and challenge the widely accepted power dynamics that place the patient in the silenced, subordinate position in a power dynamic. Medical paternalism is acknowledged and challenged on many fronts, from new narrative approaches to medical training to new laws granting patients power over their own test results. In these ways, the move toward collaboration with doctors is being fostered as a response to earlier top-down medical care; however in *Health and the Rhetoric of Medicine*, Judy Z. Segal cautions that “What seems to be a challenge to paternalism [in the form of “shared-responsibility medicine”] may be a cagey new version of it” (35). Although the

18 The anonymity of the online space prevents me from knowing the demographic details of site participants, and certainly the community members that I am talking about have access to Internet resources; therefore, I don’t want to appropriate the language bell hooks uses to a site that likely contains members of the privileged classes—especially given their access to health care. However, I believe that it is particularly useful to claim this site as a site of feminist practice that empowers and liberates women, and the term “margin” accurately describes the ways that patients are present for their care but are also silenced, left in the dark of cancer myths, not included in decision making, or not considered as whole people with material conditions that may influence treatment decisions—even when they enjoy good relationships with their doctors.

patient is given an opportunity for input in discussions with doctors, the power dynamic in these relationships remains unchallenged: “in shared-responsibility medicine, patients have a voice because they are *granted* a voice; patients are decision makers because they are recruited to decision making by experts who tell them what decisions are to be made and what the terms are in which to make them” (Segal 35). The peer community online gives voice, power, and authority to patients in a space outside the doctor-patient relationship. Despite moves toward sharing responsibility for decision making in health-care, “There are ways in which the new physician is still the god-like practitioner but one whose job description includes caring what the patient thinks” (Segal 35). However, caring what the patient thinks still falls short of a true collaboration. We have been socialized to accept the “god-like practitioner,” so when patients seek out a voice, they often turn to online communities where they can share their experiences without the oversight of doctors. While there are dangers lurking in the anonymous, virtual, amateur advice-giving sites dedicated to health and wellness, there are treasure troves of archived online writing from collaborative threads that can provide an evaluative critique of medicine in practice. These spaces are real challenges to top-down, paternalistic medical care. Here, as in other areas of women’s rhetoric, experience is valued and silenced voices are heard. The collaborative online narrative does not lead to consensus; rather, it provides a fuller picture of the experience of patients. There is room online for asking questions, for seeking clarity, for varied efforts to control and understand. And what also becomes very clear is that patients come to this space because in the traditional medical community patients do not control healthcare.¹⁹ The desire to make sense of one’s illness, even in this community space, is different from an attempt to come to a consensus about illness.

In the end, to use the language of the online community, the OP (original post) got B9 (benign) results and left our community, but the resulting thread left a lasting impact on the women who shared their stories. I participated in this thread when I was about a year out from my diagnosis. This is how I responded in the thread:

I went in for a mammogram because I felt a lump. The technician said that I had dense breasts and so I needed an ultrasound. They stopped being really friendly and were suddenly very professional and distant. The radiologist came in and said directly, “I’m really worried.” Yeah. Me too. That was a Friday. They got me an

19 Of course, it can be argued that doctors do not “control” healthcare either. I do not claim they do; however, this online space can be an empowering location for patients who often feel powerless in their illness and treatment.

appointment with a surgeon the next business day. I knew. On Monday, the doctor looked at me and said, "You probably have cancer." He tried to book a lumpectomy right then and there. (I went alone...might as well...I knew already.) I made him do a needle biopsy because I needed to KNOW 100% before I went ahead with any other procedures. He asked me if I would like to come in for the results and I said, "Doc, we both know I have cancer. So, you're just going to tell me how bad it is. That we can do over the phone." He called a few days later with my diagnosis.

After that, we went down to Boston to Dana Farber for a second opinion, and I got on a clinical trial. I was anxious to move ahead, but in the end it was so much better for my prognosis that we waited and got a second opinion.

This discussion thread provided a space for us to slow down and share. I went on to craft a longer diagnosis narrative after the post above, and that narrative led me to turn a critical lens toward this extracurricular space leading to this project. The thread fizzled out with many women expressing their thanks specifically to the OP—some even reported that they cried upon hearing her good news. The OP's final post was:

Wow! I'm so glad that I started this thread! Reading all of your experiences has helped me understand what I'm experiencing. You are also answering a question I hadn't even thought of: Do they say comforting things even if they can see that things aren't looking good?

-WorriedMama

The gratitude expressed by the community for the opportunity to share the stories of their diagnoses was striking. The OP was aware that some members of the community looked back on the time of diagnosis as a traumatic experience: "Everyone, thanks so much for sharing so openly about a tough moment in your lives. I hope reliving it hasn't been too traumatic. Maybe it's given an opportunity to look back and see how far you've come?" WorriedMama's acknowledgement of the "openness" of the community is an indication of the success of de-mythicizing the experience of the breast cancer diagnosis. That open exchange is why she came to this community, and that was the feminist response she received. Another community member posted, "This is a great thread by the way. Interesting to hear how others heard. Praying that the person who started this thread hears good news." And although the OP is gone from the community, the thread remains part of the archive. It can be searched for and revived. It can be read and learned from. It can continue to share the kairotic moments of diagnosis and the collaborative voice of patients and their experiences. And more than any individual response,

it can reflect the complicated and diverse nature of cancer and work toward de-mythicizing breast cancer.

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