

**Blogging Chronic Illness and Negotiating Patient-hood:
Online Narratives of Women with MS
by
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A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the requirements for the Doctor of Philosophy, The City University of New York

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This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement of Doctor of Philosophy.

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Abstract

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Personal narratives about women's everyday lives with chronic illness are mapped onto the landscape of social media through blogging. Social media is facilitating an already-existing shift in patients' roles as they are increasingly enabled and expected to self-educate themselves about their illness, collaborate with providers, self-manage their care, and engage in health activism. The health care industry has seized on the widespread use of social media to bolster rhetoric that the accelerated knowledge development made possible through social media has the potential to revolutionize the practice of medicine. Critics, however, argue that responsibility and activism via digital technologies has become an obligation of patient-hood that reproduces and masks neoliberal disciplinary practices that are embedded in health care. Lost between the divergent viewpoints of industry advocates and academic critics is the voice of patients whose use of social media blurs the boundaries of these ideological distinctions through their lived experience.

Women with chronic illness "practice patient-hood" in part by using social media in the negotiation between the opportunities available to them and expectations placed on them. Blogging can be understood as multiple concurrent practices: empowering, resistant,

and disciplinary. As an empowering practice, bloggers seek and find mutual understanding, form social networks, share experience, and create new knowledge. As a resistant practice, bloggers challenge medical authority, negotiate social expectations, and direct new narratives that may help to de-stigmatize serious illness. As an act of participatory patienthood, blogging reproduces the disciplinary practices characteristic of the neoliberal shift in health care and support services from collective to individual responsibility. Specifically, this study examined blogs written by women with Multiple Sclerosis using a three-part methodology: an ethnographic content analysis and close reading of blogs as life narratives (N=40); a survey of bloggers (n=20) about their blogging activities; and a five-week online discussion forum with bloggers (n=9) about their experiences with blogging about their lives with a chronic illness. In addition, the research envisions the online environment as a material, co-created and mediated space in which bloggers enact these complementary and contradictory practices.

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PROLOGUE

All researchers are guided to some extent by personal experiences that shape their worldview, draw them to certain academic disciplines and interests, and influence how they carry out, interact with, react to, and interpret research. Fortunately, the practice of self-reflection is now commonplace in social science, with many thanks to feminists who rightly insisted that the personal is political. Even without critically engaging in reflexivity, which is not my goal here, I think it is fascinating and fruitful for researcher, participant, and reader alike to know where the researcher stands in relation to her project.

I came to this project from a life-long nearness to chronic and terminal illness. Despite attempts to interest myself in research topics that I could assume more distance from, my experiences, and all of the deeply felt emotions that accompany them, have guided my focus back to the lived experience of illness. By engaging in this research, perhaps I continue to try to articulate feelings and experiences for which words seem inadequate.

I grew up surrounded by illness. For most of my childhood, one of my parents was ill at any given time. When I was two years old, my mother barely survived leukemia. Brutal rounds of chemotherapy forever changed her body and her health. Her energy levels never returned to what they had been (although, much to her credit, she has always made the most of the energy she has when she has it), and she has since lived for many years with a collection of chronic illnesses. My father survived cancer once but not the second time, and died when I was almost twelve. The spectre of the hospital and its artifacts seemed always present in our house, the most obvious being the hospital bed that occupied my parents' bedroom for the months before my dad's death, but more abstractly, the awareness of

frequent visits to doctors and hospitals and the various tests and treatments that were performed there. In more recent years, another family member was diagnosed with Multiple Sclerosis, and for years, my life has been shaped by a doggedly persistent and pervasive anxiety disorder. Needless to say, my family did not win the genetic lottery.

Through these intimacies, I have witnessed and lived the negotiation of everyday life that illnesses require. I am familiar with the feelings of insecurity that disease and death often produces. I was made sensitive to the social taboos and isolation American culture attaches to illness and death, and learned early on to negotiate the social stigmas that are the remnants of contemporary American society's pathologizing and denial of death, and with its obsession with holding on to life.

Like the participants in this study who seek connection with others who share their illness, I have felt the immediate connection that forms when someone else shares your unique experience with illness or death; when someone "gets it." It's a feeling of relief, of being able to let your guard down, of empathy for raw emotions. Personally experiencing these moments of connection has influenced a long-held interest I have had in investigating how and why people seek and find mutual understanding, form networks, and share experiential knowledge that fills in the gaps created by diagnoses and treatment. I admire the courage it takes to articulate difficult experiences, resist social expectations to remain politely silent or relentlessly cheerful, and direct new narratives that help to destigmatize serious illness. Perhaps ironically, formalizing these supportive networks can sometimes produce tyrannical rhetorics of prescribed ways of "coping" or "healing," and which may be somewhat isolating for a person whose experiences do not align with the program. I found this with my own experiences with support groups. Nevertheless, I see efforts to organize

around acknowledging experiences and emotions that others wish to silence as optimistic acts.

My earlier academic work focused on the physical spaces in which support groups took place and how the physical environment influenced, facilitated and documented the emotional work that went on there. The research revealed contested beliefs about therapeutic approaches and highlighted that while formalized programs and physical containers create safe space to express stigmatized emotions, they can also reproduce social norms by turning emotions into things that need to be produced, processed according to program, and tucked neatly away.

My second interest in this area of study is my passionate belief in health care as a fundamental human right and the importance of equal access. This, too, was partially acquired through personal experience. As a young adult navigating the health care system on my own, I quickly learned how much time, energy, and effort it took to manage illness, seek doctors I respected and who I felt respected me (and deal with the affront of doctors who clearly did not), and handle health insurance claims and seeking access to care. This was made more difficult during a period of time when I did not have health insurance and was unaware at the time that I could have applied for Medicaid. I got through by seeing a doctor who bartered with a pharmaceutical representative for free samples of the prescription medication I was taking and sought other care at a public clinic. It was during an encounter with a condescending doctor at a public clinic that I experienced first-hand the disparity in health care between those with resources and those without. Up until that point, I had always had good insurance and easy access to quality care. I had the social capital of education and privilege and was already an experienced navigator of the health

care system. He treated me so poorly that I couldn't imagine the effect his behavior would have for people with fewer resources, more serious health concerns, or less ability to advocate for themselves. I should note that I have also received excellent care at public health clinics, but this incident made me realize that people who depend on public resources have fewer options for their care and can't do much about it if they encounter providers like the one I did. Most of the women in this study were like me, with the exception of the period of time I just described. They had insurance, access to quality care, education, and social support and other resources. They also had similar obstacles and frustrations in negotiating the system that for many of them included public assistance programs such as disability benefits. While most of them didn't experience disparities to the same degree as people with fewer resources, focusing on their experience with patienthood as it is told through blogging begs comparison: Where are the voices of those who do experience those disparities and whose voices are silenced for numerous reasons?

As I began to think about writing this dissertation, I imagined two scenarios: a person with illness who wants to give voice to her everyday experience; who wants to connect to others but might be prevented by geographic, physical, or other limitations; and a "return" to the grass-roots spirit of creating communities of support yet unhindered by formalization and institutionalization. Where else might people go to make these connections, band together, and practice resistance? Online, of course! What follows is an exploration of the voices of women who choose to share their lived experience with chronic illness and, in doing so, give us a glimpse into what it is like to be a navigate their lives and be a patient in the current culture of American health care.

CHAPTER 1: INTRODUCTION

Locating the study

Internet social media applications are a unique location to read narratives of women's experiences with illness because they provide insight into lived experience as told through a public forum. A shift toward a more interactive online environment, commonly called Web 2.0, is changing how information is shared and communicated. Social media has facilitated the sharing of health information between users and the co-creation of new knowledge that is shaped by personal experience. Applications like blogging are also helping to facilitate an already ongoing shift in patients' roles (Conrad 2008; Fox & Ward 2006; Lenhart & Fox 2006) in which they are increasingly both enabled and expected to become technologically-empowered citizens who actively strive to participate in their care, collaborate with providers, self-educate and educate others about their illnesses, and self-manage their care. While individuals have initiated many of the social media practices related to their health, the health care industry has promoted them as part of a model of "participatory" patient-hood that advocates argue that has the potential to "revolutionize" health care. They argue that accelerating knowledge development and contributing to advances in research will ultimately improve health treatment and outcomes.

Critiquing this idealized construction are academic scholars who claim that the rhetoric of patient empowerment through participation masks the ways in which neoliberalism succeeds in disciplining us *through* regulating ourselves. Rose (1998) writes that we act as "enterprising selves" in our efforts to fulfill a cultural ideal of a moral, productive, and successful citizen. Furthermore, he and Novas (2002) extend this idea to the body as a site of regulation and discipline in their conception of us as self-monitoring

biological citizens. So while patients are more *enabled* to take on a greater role in their health care, they are also *expected* to do so in order to strive toward these ideals. From this perspective, the promotion of social media in personal health practices facilitates these forms of governance. It also succeeds in helping to reconstruct collectivism, which is typically a dirty word in neoliberal-speak, as discipline rather than solidarity.

As Foucault (1980) conceived, discipline of the citizen is achieved most effectively through the indirect means of guiding individuals to discipline themselves. Under neoliberalism, the political, social, and cultural ideal of an “enterprising self” (Rose 1998) reproduces the reductive effects of neoliberalism. More specifically, the ideal conception of the patient-citizen has come to include using digital technologies to acquire and share information in order to direct, manage, and improve one’s health. In using the internet and social media in these ways, individuals are portrayed as empowered through the technological tools that give them unfettered access to health information, and they are expected to use them. In framing these practices as acts of choice, the shifting of responsibility from the collective to the individual is simultaneously celebrated and its negative effects downplayed.

While neoliberalism is ideologically opposed to collectivism, the potentials of social media to produce data and influence large numbers of people provide another venue through which to discipline and profit from citizens. Individuals are encouraged to donate personal data and perform labor in the name of furthering medical innovation, thus benefitting the greater population, whilst industry and the state profit both directly and indirectly from their efforts. A rhetoric of health activism reorganizes collectivism and turns it around so that it is no longer an oppositional practice, but a cooperation between

private, public, and personal interests. The promotion of practices such as using social media to self-discipline can also be seen as reproducing structural inequalities by deflecting attention away from the inadequacies of the state to care equally for its citizens and through excluding people without the resources to engage in participatory patienthood.

Lost between the divergent viewpoints of industry advocates and academic critics, however, are the voices of people who are engaging to some extent with social media related to their health and illness. These participants in social media blur the boundaries between these ideological distinctions through their lived experience with illness. In practice, patients must negotiate between these perceived opportunities and obligations to meet their needs. This dissertation focuses on the social media of blogs as narratives about life with illness, in order to understand how bloggers, as I will argue, “practice patienthood.”

Web 2.0, has generated new forums for patients and advocates to share health information in which users can become "prosumers" who both produce and consume content (Daniels 2012; Ritzer and Jurgenson 2010). Miller and Pole (2010) credit the user-generated content characteristic of this interactive environment with being responsible for the rapid growth in health-related content online and call blogging the "quintessential Web 2.0 application" (p. 1514). The internet has been conceptualized as an important location for laypeople (i.e. patients and caregivers) to share health information, give advice, write personal narratives about illness, connect to others with illness or those affected by it, and share emotional support among a wider, more accessible network of users. For the most

part, studies of these practices have shown positive effects on feelings of social support and self-efficacy (Bar-Lev 2008; Joseffson 2005; Sanford 2010; Vilhauer 2009; Weis et al 2003) although some have written about cultures in online illness communities that impose a “survivor” narrative and exclude those who do not consistently adhere to it (Ehrenreich 2001, 2010). Similarly, one of my discussion participants recalled an incident when she was abruptly blocked from an online discussion forum after a post she wrote and the grief she felt at the sudden loss of community. While studies about blogging and chronic illness are limited, there is an established literature on the use of social media by patients with terminal illness, specifically cancer (Ehrenreich 2001, 2010; McNamara 2007; Orgad 2005; Pitts 2004; Sandaunet 2008). In this study, I wanted to apply some of the same concepts to a different illness experience and these studies were a good starting point.

The internet is a social and spatial medium that has rapidly become integrated into our daily lives and with which we map and reshape our experiences, identities, and social roles and structures. As a newer field of study, scholarship about the internet is far from comprehensive, especially given its diversity, breadth, and ever-changing nature. The broad and immediate reach provided by social networking prompts questions about self-presentation, negotiating public identities, the nature of online connections, and conceptualizing and situating the online experience. While social media plays a significant role in contemporary American culture, it is most often either celebrated as transformative or demonized as threatening privacy, and is rarely critically examined. Subjecting any social phenomenon to critique is necessary in order to better understand its nuances, effects, and the mutual shaping of people and by people.

Aims of the study and research questions

In this dissertation, I seek to understand the perspective of bloggers with chronic illness, in this case, women with Multiple Sclerosis (MS). Through an analysis of personal health blogs, a survey of the bloggers, and an online discussion forum with bloggers, this dissertation shows how lived experience with chronic illness is portrayed in online narratives, how social connections are formed through blogs, how areas of overlap between online and offline lived experience are negotiated, how blogs are situated in larger social practices and structures, and how experiences of being a patient with chronic illness in the current American health care system are reflected and enacted through engagement in social media.

Four areas of inquiry guide this study:

- 1. How do women with chronic illness narrate their experiences with illness through blogging?**
- 2. How do they connect to other women bloggers with MS and what is the nature of those connections?**
- 3. How are their blogs situated within and shaped by larger political, social, and cultural structures?**
- 4. What is their perspective on being a 'participatory' patient and how is it enacted through blogging?**

The choice for a case study of blogs written by women with MS is fourfold: First, I specifically chose to write about women so that I could privilege their voices. A long history

of silencing women's voices, particularly discourse surrounding their bodies, coupled with the carryover of problematic gendered norms and practices onto the internet (Herring et al 2004; Pedersen & Macafee 2007) (discussed further below) make this an important approach. Second, I chose to focus on serious chronic illness because the embodied experience requires the person to confront it daily and negotiate their lives with it in a way that is different from people without serious illness or with other types of illness. MS is a disease that presents with a wide variety of symptoms, affects people with the disease in different ways, and often fluctuates in severity over the life span. Third, MS affects women two to three times more often than men. Fourth, current social science research on the intersections of social media applications and illness is limited and there is a small but active blogging community that provides a rich source of data.

Organization of the dissertation

In Chapter 2, I focus a literature review in four primary areas. First, I outline how the political, economic, and philosophical doctrine of neoliberalism shapes the current system of health care in the United States, how it affects structures and practices of health care, and how it impacts the individual patient. Second, I discuss the social construction of patient-hood, rooting it in a historical context that describes changes in the health care industry over time. Third, I propose a theoretical framework for understanding the internet as spatial. This framework is rooted in environmental psychology, which views phenomena as situated in larger socio-spatial practices. Finally, I discuss the study of narrative, particularly illness narratives. I demonstrate that the blogs in my study can be

considered as part of a history of women's illness narratives, but that they depart from them in several significant ways.

In Chapter 3, I outline my methodology. First, I offer a rationale for studying blogs and bloggers. Second, I discuss the internet as a field of study and some of the methodological challenges it poses. Third, I focus specifically on the study of blogs. Fourth, I outline the ethical considerations I undertook in designing the study. This topic is worthy of attention because the internet is a relatively new field of study with few established, and sometimes contested, ethical research standards. Fifth, I outline how I dealt with these issues when applying for Institutional Review Board (IRB) approval of the project. Sixth, I outline my three-part methodology: an ethnographic content analysis of 40 blogs; a survey of 20 bloggers; and an online discussion forum with nine bloggers. I describe my sample and the sampling strategies I undertook. Lastly, I outline my data analysis.

In Chapter 4, I describe a basic overview of the blogs and bloggers in my sample, including characteristics of the blogs and bloggers, patterns of blogging, and introduce the topic of writing to a public audience, which I take up further in the next chapter.

In Chapter 5, I discuss the theme of narrating chronic illness online, arguing that blogging about this taboo subject helps to counter stigmatizing social constructions of illness and disability. I also argue that bloggers write with an acute awareness of audience and negotiate their written voices in relation to a socially-constructed meta-narrative of positivity.

In Chapter 6, I discuss how the bloggers in my study "practice patient-hood" in their negotiations with the health care industry. From the online discussion with bloggers

(Phase 3), I found that while they are aware of the pressures on them to be “participatory” patients, many of them preferred this role and/or viewed it as a necessary part of being a patient in the current American health care system. I found evidence of greater resistance to one particular aspect of the health care system, which was fund-raising and advocacy. This finding highlighted gaps in institutional supports for people with MS. Furthermore, I argue that a patient’s ability to engage in participatory patient-hood is contingent on her having sufficient resources as well as health care providers’ support of these practices.

Finally, in Chapter 7, I conclude the study, describe contributions, limitations and implications, and make recommendations for future research.

Summary

Studying blogs provides a way to analyze how women narrate their daily lives as people with chronic illness and can tell us about what it’s like to be a patient in the current health care system. With this in mind, this dissertation demonstrates how writing a personal health blog plays a role in a new kind of patient-hood, one that places individual responsibility and collective advocacy and activism as central tenets. I examine the intersections between the strong messaging and implicit expectations of the state and health care industry and the ways in which patients engage (or not) in participatory patient-hood. While the participants in this study represent a small minority of the approximately 250,000 American women with MS,¹ their blogs tell us much about what it

¹ Source: <http://www.medicalnewstoday.com/releases/40510.php>

The number of cases of MS is not tracked, but the National MS Society, the leading advocacy group in the United States estimates that 2.1 million people worldwide and 400,000 Americans have it. In general, the disease affects women twice as much as men, yielding the estimate of 250,000.

is like to live with the disease and some of the opportunities and challenges facing them as patients. I examine how these public narratives demonstrate the role of online technology in patients' daily lived experience.

CHAPTER 2: LITERATURE REVIEW

This literature review is organized into four distinct categories, which together create the context in which this study is situated. In the first section, I outline how the political, economic, and philosophical ideology of neoliberalism shapes the current culture of health care in the United States. I examine how it affects structures and practices of health care, and ultimately affects the individual patient who must navigate a complex system that has increasingly shifted burdens of access, cost, and health management onto the individual.

Secondly, in order to illustrate how contemporary patient-hood developed, I outline a historical context of how patient-hood has been socially constructed over the past two centuries. I focus on the institutionalization of medicine that profoundly shaped the primary figures and relationships in health care practice and policies, and the role of the women's movement of the 1960s-70s in challenging patriarchal practices.

In the third section, I describe the environmental psychological orientation of this study, namely through conceiving of the internet as socially-produced space. I further illustrate how internet technology and humans mutually shape one another by describing the internet as socially-mediated.

Finally, I discuss the mechanism of studying narrative as the primary focus of this dissertation. I describe the tradition of women's illness narratives and place blogs in this trope, arguing that they are a continuation of this history yet depart from it in several significant ways.

Medical neoliberalism and empowerment rhetoric

In this section, I describe how contemporary patient-hood is shaped by the effects of neoliberal capitalism on the health care industry or, as Fisher (2007) terms, “medical neoliberalism.” I then describe how social media has been incorporated as a mechanism for furthering neoliberal rhetoric of patient empowerment that can be seen as masking state and health care industry interests in disciplining citizens.

Neoliberalism seeks to disentangle capital from the constraints of social welfare systems such as health care (Harvey 2005). The increasing privatization and commoditization of health care in the United States and disinvestment in public welfare by the state that are the result of neoliberal policies, ultimately have direct impact on people who need health care (McGregor 2001). Increases in costs, limitations to access, and reductions in supportive services and benefits shift greater burdens onto individuals and widen disparities. The impact of neoliberal policies are felt more harshly by the poor and the sick who generally have fewer resources to fill the gaps left under these conditions. For example, until the recent passage in 2013 by the U.S. Congress of the Affordable Care Act, insurance companies could refuse coverage to people with “pre-existing conditions,” cap costs, or drop sick patients from their policy. By shedding themselves of costlier responsibilities, privatized health care institutions made greater profits off of the backs of healthier patients. This legislation was historically significant, yet it remains to be seen what real effects these policy changes will make on the lives of everyday people who need health care. While it addresses some major problems of basic access and security of coverage, the legislation fails to address other costs and limitations that affect the patient on a daily level or seriously challenge the structural inequalities of the health care system.

The health care industry includes multiple competing interests, all of whom seek to discipline and thus profit from the body in some way. The state seeks to benefit from a healthy, and therefore productive and generative citizenry (Foucault 2009) yet it shoulders the financial burden of the uninsured or underinsured. On the other hand, medical providers such as hospitals and doctors are incentivized to increase billable services, both to profit from services and recoup costs spent on treating the uninsured or underinsured. Health insurance companies seek to maximize profitability through charging high premiums and co-payments and limiting care. And pharmaceutical companies, medical device makers, and other manufacturers seek greater consumption and sale of their products. The voices of people who must become patients, and who typically have little choice in whether or not to receive health care, are often drowned out by this powerful collection of forces.

Fisher (2008) further describes the characteristics of medical neoliberalism as occurring at the levels of policy, institution, and culture. At the policy level, limitations of the current health care system are portrayed not as a problem of the system itself, but as opportunities of patient choice. At the institutional level, the commoditization of health services and products turn patients into consumers who assume some of the burden of the free-market system. Fisher (2008) writes “unlike patients, consumers seeking health care bear the responsibility for the choices they make – or fail to make – regarding their health” (p. 4). Finally, at the cultural level, the body itself is commoditized into parts, diseases, etc. rather than a whole body. This can be seen as a continuation of a history of biomedical practice that objectifies, medicalizes, and breaks the body into diagnosable and treatable parts. For example, a neurologist, whose expertise is specific to the nervous system,

generally directs medical care of MS. The treatment of the disease often includes expensive tests like MRIs as well as costly pharmaceutical regimens. This history has particularly impacted women (Ehrenreich 2011), racial minorities (Bhopal 1998), and the poor (Crawford 1977). I will address this history, as well as feminist critiques of these perspectives and practices, later in the chapter, but call attention here to the division of body parts or specific diseases into billable units.

As Fisher (2007) writes, neoliberalism works dichotomously so that as the state transfers responsibility to its citizens to provide for themselves, it simultaneously increases the amount of monitoring of citizens' actions. One way it does this is by orchestrating a rhetoric that frames the free-market policies that have reshaped economic and social situations as opportunities for choice, rather than as limitations or constraints. Furthermore, it seeks to make the individual complicit by framing the citizen as both empowered and responsible for those choices, thus reproducing the rhetoric and monitoring ourselves. To paraphrase a Foucauldian (1980) argument, one mechanism of indirectly imposing disciplinary control is by creating norms against which to measure ourselves and attempt to adhere to. It is in these attempts that we facilitate the state's goals of disciplining us.

Social media has created a new modality for the transmission of health information, increasing the amount and speed of its delivery. Digital technologies and social media have become so integrated in shaping a new cultural paradigm of health care that some in the industry have coined the term "Health 2.0," which Sarasohn-Kahn (2008) defines as "the use of social software and its ability to promote collaboration between patients, their

caregivers, medical professionals, and other stakeholders in health" (p. 2). Eytan (2008)

best describes the concept's ideological goals and rhetoric:

Health 2.0 is participatory healthcare. Enabled by information, software, and community that we collect or create, we the patients can be effective partners in our own healthcare, and we the people can participate in reshaping the health care system.

Such impassioned and enthusiastic rhetoric found in the quote above is common among advocates of this approach, illustrated here by such terms as 'partners,' 'participate,' and 'reshaping.' However, this rhetoric can be seen as merging the "responsibilization" of the self (Shamir, 2008; Thompson 2007) with the increasingly widespread use of digital technologies in order to reproduce disciplinary practices (Lupton 2012).

Increasingly, this participation calls not just for the creation of knowledge, but for the commoditization of it as well. One clear example of how rhetoric of neoliberal disciplinary practices, which is couched in terms of individual responsibility but which obscures state intervention, is the growing trend for patients to publicly report their personal health data on the internet through health social networking websites. A discourse of collectivism and empowerment is employed to encourage users to donate the data in the name of medical advancement. In some cases, the aggregated data is anonymized and sold by the company who maintains the website to health care companies for profit.² Interestingly, the fact that the data is sold for profit is incorporated into the public relations messaging as contributing to medical research and development.

² The most well-known company in the United States that operates under this model is patientslikeme.com

Levina (2012), who is critical of the empowerment rhetoric that is an inherent part of Health 2.0, and especially of voluntary data reporting, writes that it creates the perception that using new technologies allows "active patient citizens" to align themselves with acts of rebellion against the traditional medical patriarchy. However, this can obscure potentially problematic aspects such as ethical considerations of selling freely-given data. Other critics of this form of medical neoliberalism argue that a potential consequence of the increase in patient participation is exploitation by the state to discipline bodies and maintain their productive value and/or commoditize illness, which Foucault conceptualizes as *biopower*. Rose and Novas (2002) argue that the state constructs patients as "biological citizens" whose bodies are the site of self-regulation and responsibility. They argue that "activism and responsibility have now become not only desirable but virtually obligatory" (p. 22) to fulfilling the patient's role as a supposedly equal participant. These expectations are partially the product of public and private institutions that seek to discipline citizens by constructing personal responsibility as a moral imperative, and an act of empowerment and autonomy (Thompson 2007). As Wathen and Harris (2007) describe, numerous critics question the clinical value of the information-as-empowerment model and whether these policies and practices are of greater benefit to the patient or the health care system:

Accompanying the current discourse on health care reform, in which terms such as *patient empowerment* and *self-care* often appear, is the assumption that health-informed individuals will participate, alongside their health care providers, in a process of shared decision making. Ultimately, the logic follows, informed empowered patients will take responsibility for their health, including managing their health care (p. 640, emphasis in the original).

The authors note that these assumptions have been found inconsistent with the reality that patients may not be able to or may not want to shoulder the responsibilities for themselves

or their families. For the participants in my study, all of them seemed able to take on the responsibility to some extent, and, whether they wanted to or not. They seemed to feel they had little choice in order to feel confident that they were receiving the best care and exercising as much control over their disease as possible.

Picking up on laypeople's use of the internet to inform themselves and others about health, many companies, organizations, and agencies in the public and private sectors of the health care industry have rushed to position themselves in the social media landscape in order to market, shape, and influence their sectors of the economy as well as influence policy. They use the internet to promote a rhetoric that participation in social media is inherently empowering and that patient engagement via this media will revolutionize health care for the collective benefit. Examples of this include the websites of health insurance companies, advocacy organizations, and other industry stakeholders that feature patients as pseudo-experts who blog or appear in video presentations. While these may highlight the significant experiential knowledge patients have acquired and developed on their own, framing self-informed patients as a new kind of "expert" implies that this kind of engagement is an empowering act of choice rather than a necessity in order to advocate for themselves in a system of inequality.

If "prosumption" (the production and consumption) of health information via the internet is an added responsibility of contemporary patient-hood, only certain people are even able to participate in these activities, if they choose to. A person needs access to the internet (typically via broadband), internet literacy and digital fluency (Green 2006). Those who lack these resources and skills, who are disproportionately poor, are at a disadvantage, missing out on opportunities of the potential benefits of these practices.

Rose and Novas (2002) argue that the paradigm of biological citizenship includes the use of internet technologies to engage in necessary practices, creating a *digital* biological citizen. Using social networks to participate in producing medical and experiential knowledge can also reproduce inequalities that remain embedded in the current health care system. It may also further the interests of dominant institutions that profit from a person's suffering. In these ways, social media can also be a tool of medical neoliberalism.

In practice, the patient is constrained by a need for care and little influence over an unwieldy bureaucracy. Facing such odds, they are left with little choice but to navigate their way through the system, advocating for themselves and their families as best as they can. As one of the discussion participants stated, she viewed taking responsibility of self-educating, keeping track of, and advocating for their care as simply part of being a patient. If this is the case, as many of the participants in my sample seemed to believe, I argue that using social media to acquire, share, and create knowledge can be empowering, especially *under the current conditions* created by medical neoliberalism.

The “enterprising self” and “biological citizenship”

In this section, I will more thoroughly describe Rose's work on the “enterprising self” (1998) and Rose and Novas's work on “biological citizenship” (2002) and how these concepts inform this study. These theoretical concepts shape a framework for understanding the perceived role of medical patients in the current health care systems of advanced liberal democracies. Their work builds on Foucault's (2003) conceptions of the

political, institutional, and ethical mechanisms through which power is enacted. Power, as Foucault (2003) argues, works through, not against subjectivity and transverses all practices, at all levels, “through which persons are ruled, mastered, held in check, administered, steered, guided, by means of which they are led by others or have come to direct or regulate their own actions” (p. 153). His conception of “governmentality” describes how political, military, economic, ideological, medical, and other authorities oversee and direct us toward certain “desirable states [such] as health, happiness, wealth, and tranquility” (p. 153). Further, we are governed and shaped through institutions and through ethical standards that guide our behavior in order to achieve an optimal state of being. These simultaneous technologies form a feedback loop of social reproduction that maintain state, social, and self discipline favorable to neoliberal ideology.

According to Rose (1998), a culture of enterprise fosters the self-regulating citizenry that helps maintain neoliberal governmental oversight. The “enterprising self,” (p. 151) Rose argues, is a constructed ideal of a moral, productive, and successful citizen. He writes, through practices of “initiative, ambition, calculation, and personal responsibility...the enterprising self will make an enterprise of life” (p. 154). Under neoliberalism, the duties and obligations of citizenship are re-imagined as rights and freedoms that are subjective and shaped through “acts of choice.” From this perspective, a failure to be enterprising is a failure to strive for the ideal of a moral, productive, and independent citizen; that is to fail oneself *and* society. These neoliberal ideals demonstrate, as Katz (2005) describes,

The role of the acquisition and use of skills and knowledge, the defanging of oppositional practices and positions, the reliance on newly professionalized activists to compensate for the losses associated with neoliberal policies and the

ascendance of various forms of individualism alongside a devalorization of the collective (p. 1).

Specific to this study, the acquisition of skills and knowledge, and the role of “professionalized activists” are increasingly taken up by patients. Through self-education, the sharing and co-creation of knowledge, patients assume the role of lay expert or, as one blogger called it, a “professional patient.”

Furthermore, the oppositional practices of patients who rebelled against medical paternalism in the late 1960s and the 1970s led to both the opportunities and obligations of contemporary patient-hood. In the process, the conception of collectivism has been re-scripted several times. Initially it was understood as resistant, which was empowering to citizens but troublesome for the state. It was then reconceived in the 1980s (in the United States) under Ronald Reagan. He demonized the welfare state, and painted it as promoting dependency and diluting individual initiative. More recently, as we see it demonstrated and accelerated by widespread populist networks like social media, it is re-imagined as the pooling of individual knowledge for the greater good. However, rather than a return to an understanding of collectivism as unity and an even-ing of social and economic status, there is labor to be performed in order to earn the benefits. Here, the enterprising self makes an enterprise out of producing knowledge and educating themselves and others.

Blogging can be seen as an enterprising practice that reinforces the biological citizenship. According to Rose (2006) we construct the “expert” as having the rightful claim to science and rationality. Generally the expert has some sort of professional credentials and regard their knowledge as more valuable than knowledge that is based on experience

or informal learning. Bloggers in my study performed the duties of the expert, such as conducting research and disseminating the results. They supported their information and claims with credible sources, including scientific studies and media reports. But they were careful to disclaim themselves as non-experts, since they lacked the formal credentials of scientists or doctors. Their claims to expertise was rooted in their own bodies. The information they gathered and presented was most often linked to their personal experience, and they viewed this expertise of themselves as subjective. Physicians, on the other hand, view MS from the top-down rather than the bottom-up perspectives of people with the disease. They are thus seen as having more objective knowledge, and the knowledge of specialists such as neurologists is considered especially important. The knowledge of the patient is supplementary to that of the expert. In these ways, the participatory patient is an enterprising self who performs the role of the ideal patient, and who self-disciplines through self-education, self-monitoring, and supplemental knowledge production.

More specific to health and body governance, the enterprising self is embodied in Rose and Novas's (2002) conception of "biological citizenship." In order to fulfill the responsibilities of this form of citizenship, they argue that we must we inform ourselves and take action to combat illness or even susceptibility to illness (genetic predisposition, for example) for our own benefit. Moreover, we have a responsibility to others to do these things. Three aspects of biological citizenship describe the mechanisms through which it is enacted: 1) Informational biological citizenship involves the layperson's specialized scientific and medical knowledge of one's condition; 2) Rights biological citizenship is represented by activism around a biomedical issue; and, as previously mentioned, 3)

Digital biological citizenship is enacted through virtual networks and communities that connect people with shared biological interests. All three aspects inform the practice of patient-hood explored here, and this dissertation is particularly focused on the digital practices.

The expectations of this type of citizenship are reinforced through the collectivizing that occurs when individuals organize around shared biological conceptions and identities, such as a specific illness or condition (what Rabinow (1996) calls 'biosociality'). This collectivizing yields two possible results. First, it is susceptible to being co-opted to further rhetoric favorable to the state and the marketplace, to mask capitalist interests behind rhetoric of empowerment and scientific advancement, and reproduce self-disciplinary practices. Rose and Novas (2002) argue that the advanced technologies that have altered the way bodies can be worked on, and life prolonged, create a "political economy of hope." The alternative is fear, anxiety, and dread at what one's biological future may hold, motivating us to act in enterprising ways, and shoulder the consequences if we do not.

Even though these actions are critiqued as disciplinary rhetoric, performing them can also provide opportunities for patients to gain more autonomy in their care, garner much-needed social support from each other, and lead to meaningful political change. Despite the psychological risks of potentially false hope, however, the collectivism can also lead to significant political change and alterations in the power dynamics of the medical establishment and patient-citizens. For example, Epstein (1996) has written about AIDS activists' ultimately successful efforts to pressure medical researchers and treatment providers to treat the disease as credible and worthy of attention. In doing so, and

demanding a role for patients and activists in directing research, they helped reshape the politics of biomedical research. Also, Brown et al. (2004, 2011) has chronicled the efforts of environmental health activists to achieve similar goals.

I contend that the argument of individual responsibility as either a moral duty or state discipline is overly simplistic. Of course, individuals practicing healthy lifestyles and caring for themselves have benefits for everyone: better health, better quality of life, longer life-spans and lower costs all around. As Schmidt (2007) writes, the usual liberal-conservative divide over individual responsibility on health fails to appreciate the ambiguity and complexity of the state and the individual's role in maintaining health and “it would be shortsighted to associate *any* appeal to personal responsibility for health with libertarian or rightwing ideologies.”

The situation is made more ambiguous by the fluidity between the individual patient's interests and the interests of other stakeholders. For example, pharmaceutical companies benefit from developing and selling the hugely expensive drugs required to treat MS, yet patients need and benefit from them. Advocacy organizations such as the National MS Society, which are often focused on raising money for further research, have closely aligned interests with and often receive funding from pharmaceutical companies, but rarely disclose these relationships (Rothman et al 2011), yet their efforts may help develop better treatments. Substantial resources are poured into consumer education efforts, both by the state through public health campaigns, and by the insurance, pharmaceutical, and hospital industries as cost-effective strategies. While these may constitute efforts to transfer the labor of information-seeking, they may also provide the

individual with important information. These industries have embraced the use of social media to promote a model of patient-citizenship that increases their profitability, yet individuals may feel, to some extent, empowered by using social media to engage in their health care.

The argument that the demands placed on the patients in the current political economy are necessarily burdensome is flawed when applied to the more nuanced practice of being a patient. As my study shows, some patients feel empowered by the increased ability to be knowledgeable and to participate in their care, even as they recognize the burdens and constraints placed on them. The health care system as an institution is abstract and often unwieldy, and there is little a patient can do to influence significant structural change. They can, however, acquire more skills and enact practices that help them to negotiate it to their personal best advantage.

Historical context: constructing patient-hood

In order to understand how neoliberalism came to shape health care and patient-hood in the United States, it is useful to explain the social conditions and histories of how patient-hood has been constructed. Claims of patient empowerment are historically rooted in grassroots efforts by marginalized groups (notably women; people of color; people with mental illness; environmental health activists, and AIDS activists) who shifted the medical landscape through efforts to empower patients, such as demanding greater access to information, addressing racism and inequalities in care (Nelson 2011; Smith 2005),

assuming a more active role in making decisions about their care, and a participating role in guiding the development of medical research on contested or underrepresented illnesses (Brown et al. 2011; Epstein 1991, 1996, 2000, 2009; Morgen 2002). These efforts have led to major policy changes, such as informed consent (Feden, Beauchamp & King 1986), guidelines for patients' rights,³ and greater awareness of health disparities and discrimination (Fiscella et al. 2000; Goldberg, Hayes, & Huntley 2004; Nelson 2002, 2011), as well as a cultural shift that accepted patients' rights to resist or contest physician authority. While an "empowered" patient who is knowledgeable about health and illness and makes use of that knowledge in managing his or her illness has been a commonly understood paradigm for the past few decades, social media is seen by advocates as a means to unleash its full potential. The term "empowerment" is problematic because it has suffered from over-use in uncritical contexts. It has been adopted as part of a neoliberal rhetoric of individual responsibility, which portrays the labor of individual and collective knowledge production as empowering without examining its relationships to the power structures that make it necessary. For this reason, it is important to outline a general understanding of term as it applies here. As Stavrositu (2007) outlines, empowerment is a complex and contextual concept. There are numerous interpretations but three conceptions are particularly relevant here. First, it is linked to dominance and oppression (Emerson 1962). Second, it can be experienced as self-efficacy and control over one's life

³ Such as a patient's bill of rights adopted by the American Hospital Association (http://www.patienttalk.info/AHA-Patient_Bill_of_Rights.htm). Subsequently, other professional organizations, like the American Medical Association, adopted similar guidelines. An effort was made during the Clinton administration to adopt an official patient bill of right, but the legislation failed. While there are currently no official guidelines in this format, patients' rights have been established in various forms, such as the right to privacy protected under HIPPA and some protections from health insurance abuses in the Affordable Care Act .

events, accompanied by a sense of personal responsibility and sensitivity towards others (Enns 2004). Third, it incorporates knowledge, including self-knowledge, and organizing and participation (Collins 2000). Its use in popular rhetoric about patient-hood should be examined more closely to determine what aspects of patient participation are truly experienced as empowering.

It is useful to understand the internet's current role in health care and patient-hood by placing it in the broader historical context of health care in the United States, particularly in relation to the women's health movement. Prior to the 20th Century, most medical care in the United States took place in the home, largely under the jurisdiction of women healers. While women healers were trusted by their communities for their knowledge and experience, they were often met with uneasy suspicion, and sometimes persecution, by governmental or religious authorities. In their classic work *For Her Own Good: Two Centuries of the Experts' Advice to Women* (1978), Ehrenreich and English wrote,

For centuries, women were doctors without degrees, barred from books and lectures, learning from each other, and passing on experience from neighbor to neighbor and mother to daughter. They were also called "wise women" by the people, witches or charlatans by the authorities (p. 2).

Ehrenreich & English (1978, 2010) chronicled how women's traditional role as healers came to be undermined and delegitimized in the late 1800s as white male physicians "professionalized" medicine. At the beginning of the 19th Century, medicine had begun to be drawn into the marketplace. Male doctors peddled their services, espousing the legitimacy of their methods and discounting layperson knowledge and treatment of illness. Ironically, their methods were often not based in evidence, as was traditional healing, and sometimes

did more harm than good. Because traditional healing was an integral part of community and domestic life and most healers did not seek much money or prestige, they did not attempt to compete commercially and were thus at an economic disadvantage when the pressures of the market came to bear.

The shift towards medicine as a profession was made possible by several forces: efforts to commoditize medicine and eliminate market competition posed by other practitioners, notably midwives and other women healers; the organization of professional institutions to establish and maintain new power structures; epistemological beliefs that privileged the application of scientific methods to understanding the body, and which were used as rhetoric to dismiss lay knowledge; and the application of technologies that produced rapid improvements in public health and raised public opinion about physicians.

The transition to physician dominance was not smooth. Initially, doctors faced a great deal of resistance and mistrust from the general public. The new “science” directly challenged religious authority and beliefs about the origins of disease. Medicine addressed this incongruence by equating science with progress, which did not exclude a divine plan, which resolved the conflict. Pasteur’s development of germ theory demonstrated that some diseases were communicable, and therefore preventable. Medical authorities, supported by newly emerging professional areas of social work and public health, then constructed practices such as personal hygiene as moral behaviors. Over time, beliefs that illness was caused by the will of god shifted to beliefs that health and illness were in the power of the individual and the community to prevent. Becoming ill was not the result of a spiritual transgression, but a behavioral one.

According to Foucault (1980), an epistemological shift assigned science the status of neutrality, rationality, and separation from other societal structures, and privileged it over previous epistemologies. This led to the treatment of the body as disconnected from the person and the categorization of disease as observable, diagnosable, and curable based on specific criteria. The institutions and artifacts of power that maintained these foundational assumptions became the gold standard, wiping out previous conceptions of disease and creating and maintaining a 'medical gaze.' "Unscientific" layperson knowledge, such as that held by traditional women healers, came to be disposed of rather than incorporated into new epistemologies of the body. The dismissal of women's lay and embodied knowledge undermined their influence as practitioners and knowledge producers, and subjected their medicalized and dehumanized bodies to professional (i.e. male) dominance.

According to Porter's history of public health (1998), the development of cell biology and germ theory in the late 19th Century led to the reduction or elimination of many communicable or infectious diseases, and drastically reduced the number of deaths. Likewise, improvements in sanitation and personal hygiene further reduced the incidence of some diseases. The resulting public confidence in the new and dramatic abilities of medicine accorded physicians a higher status and unprecedented power. In popular culture, scientists were constructed as disinterested and objective, apart from selfish or commercial interest. As Dingwall, Rafferty, and Webster (1988) recount, women played a significant role in promoting hygiene practices as well as establishing social reform movements spurred by industrialization, urbanization, and the poverty that was exposed. However, their roles were mostly limited to charitable and marginalized work. But while

they were excluded from the more prominent role of physician, some women helped established nursing as a suitable profession that did not contradict male doctors' authority.

According to Ehrenrich and English (1978, 2010), Starr (1982), and Cooter (2000), physicians established institutions to support and maintain the new power structures in medicine, including medical schools, credentialing, professional associations and governing bodies and specifically excluded women of all races, non-white men, and the lower classes from these institutions. Philanthropists and government agencies pooled resources into medical education and research; health care was commoditized; and a hugely profitable industry of hospitals, insurance plans and other stakeholders was developed. Government and industry heavily promoted the accomplishments and potentials of modern medicine, and consumers were encouraged to use health care services extensively. Care was moved from the home to the clinic in the name of advances in technology, and institutions such as hospitals, mental health clinics, and psychiatrist's offices reinforced the separation of the person from the body.

These exclusionary practices of professional medicine and supporting institutions gave rise to a paternalistic system that established medical expertise and authority and placed patients in a passive role for which unquestioning compliance was expected and "non-expert" knowledge was dismissed. Numerous biological states were "medicalized" into diagnosable conditions, including women's menstrual health, childbirth, psychological states, and homosexuality. Public health campaigns constructed campaigns around desirable and undesirable conditions, such as the promotion of eugenics. Ehrenreich (2011) chronicled the lengthy history of mostly-male experts problematizing and

medicalizing women's bodies, diminishing female knowledge and embodied experience. Women's knowledge, gained from first-hand experience as traditional caretakers of the family, was relegated to folk medicine and while care of common minor illnesses was kept in the home, it was indirectly dictated by "approved" medical practices. As Morgen (2002) writes, "medical knowledge was used to justify women's secondary place in society; exploit women as consumers of medical care; rationalize racist health practice and a health system that provided class-stratified services; and exclude women from positions of importance within the hierarchy of medical occupations" (p. 122).

Constructing contemporary patient-hood

Two developments facilitated a profound shift in health care beginning in the 1960s and 70s: push-back against medical paternalism by feminists (Morgen 2002) and other political activist groups, such as the Black Panther Party (Nelson 2011); and a reversal in how health care was represented by the state and the health care industry that was in line with shifting neoliberal policies.

Several groups began calling attention to the gross imbalances of power between health care providers and patients, and the institutional abuses of some patients, and pushed for reforms and cultural change that allowed patients a greater role in their care. The mental health movement (also called the "consumer movement") called attention to forced institutionalization and abuse and argued for greater participation and consent by the patient, and even argued against the concept of patient-hood (Frese & Davis 1997). The

self-help movement privileged non-expert knowledge, provided the social and emotional support that was lacking in so many medical interactions, and attempted to give patients a collective voice against medical hegemony (Banaszak-Holl, Levitsky & Zald 2010). The feminist movement called attention to power differentials in doctor-patient interactions and sexist assumptions and practices, and focused greater attention on women's health issues (Morgen 2002). And political pressure by rights' groups influenced the creation of the Medicare and Medicaid programs in 1965, increasing access to health care for millions of poor people and senior citizens and establishing new rights of citizenship (Banaszak-Holl, Levitsky & Zald 2010).

The impact of the women's health movement on patients' rights is described by Morgen (2002) as transformative:

In 1969, a woman who placed herself under a doctor's care had the duty to do what she was told. Now she has the right to gather information and resources to make her own decisions about her sexuality, her reproductive life and health, even her treatment for breast cancer. Not all women want to exercise that right. But the commitment of the women's health movement to autonomy and informed consent has transformed health care in this country for women (and for men). (p. 11)

As Morgen (2002) describes in her comprehensive history of the women's movement and health care, organizing began at the grassroots level with women demanding access to information about their bodies and medical treatments. Activists engaged in collective efforts to self and peer-educate, create and disseminate information, provide services that were otherwise not available (such as safe abortions), and affect policy. Notable developments included the creation and publication of educational literature, such as the landmark *Our Bodies, Ourselves* in 1971 by the Boston Women's Health Book Collective; the

establishment of clinics by the Federation of Feminist Women Health Centers; the work of women who travelled around the United States offering workshops on cervical self-examination; the establishment of the Jane organization which worked underground before *Roe v. Wade* to provide safe and low-cost abortions, often performed by trained layperson members of the organization themselves; and activism that exposed the potentially harmful effects of birth control pills and pressured the Federal Drug Administration to require prescription drug producers to provide information to consumers. Notably, black women activists organized and founded the Black Women's Health Project to shed light on the health concerns of non-white, less-privileged women whose needs and experiences were not adequately addressed by the largely-white feminist movement. Similarly, women formed organizations for Latinas, Native American women, and Asian women.

The response to feminist activists from the medical community was a mix of hostility, reluctant acknowledgement of the legitimacy of feminists' demands, and limited support. Eventually, however, specific attention to women's health issues and greater transparency became more widely practiced. However, as Morgen (2002) asserts, the mainstreaming of women's health diluted some of activists' goals, and led to cooptation of women's health care services for profitability. While the women's health movement created a foundation for better women's health care overall, its specialization became part of the industry's "diversification strategies" (p. 146) to compensate for cuts in insurance coverage of services by creating new markets. The accompanying rhetoric adopted some key features of the feminist model and utilized terms such as collaboration, empowerment, self-education, and pro-woman. Also, some of its empowering practices, such as self and peer education and self-help groups were implemented and promoted by industry because

they were cost effective. A similar cooptation of language is currently taking place through the promotion of social media as a practice of participatory patient-hood.

Simultaneous with, and facilitated by, patient push-back, the state's previous promotion of the use of health care services shifted to pressuring individuals to assume greater responsibility and use less health care (Cooter 2000). This reversal resulted from the convergence of demand for greater access to health care, economic pressures of dramatically-rising health care costs, and the state's shift toward neoliberal policies that reduced the state's role in providing access to health care for its citizens. Likewise, the health care and insurance industries began pushing the mantra of individual responsibility for maintaining one's personal health in order to prevent disease. John Knowles (1977), a prominent physician and then-president of the Rockefeller Foundation, famously argued that with vast improvements in eliminating and preventing infectious disease through improvements in sanitation and personal hygiene, improvements in nutrition and interventions such as vaccination, the remaining individual health problems are largely the fault of the person. According to him, people are born healthy and make themselves sick through their behaviors and choices. He argued that people have the right to information and accessible services but there is a "moral obligation to preserve one's own health – a public duty if you will" (p. 50).

Crawford (1977) argued that these assertions blame the victim and are used to justify inequality and cost-shifting. For example, while the poor were previously criticized for not using enough health care services, they were later blamed for using too many. He argues that blaming the victim ignores what is known of human behavior, minimizes the

environmental impact that is beyond the control of the individual, and disregards structural, political, and economic realities that contribute to poor health. At a time when grassroots self-help groups were a relatively new concept, Crawford (1977) wrote,

...the ideology of individual responsibility threatens to incorporate and use the self-help movement for its own purposes. Self-help initially developed as a political response to the oppressive character of professional and male dominance in medicine...However, because the movement has focused on individual behavior...it lends itself to the purposes of victim-blaming (p. 664).

Echoing Crawford three decades later, Brown et al. (2011) note that the medical establishment can repurpose patient activism for its own goals:

Once an illness is medically recognized, the movement may be co-opted by medical institutions that exert control over treatment, research, funding and can work to exclude alternative etiological explanations" (p. 123).

That is, medical institutions may seek to limit the explanation of the causes of a disease so that they can maintain control of scientific discourse and knowledge-production, make claims to finding cures, dismiss alternative treatments, or silence uncertainties about standard treatments.

Constructing a spatial understanding of the internet

In this dissertation, I examine the intersections of the digital and the material through the interdisciplinary lens of environmental psychology, which places the focus of

study on people's experiences-in-context(s). As implied by the plural spelling, this perspective makes clear that settings and scales overlap to form and create multiple and interstitial contexts in which to locate the subject. In this case, I examine the online environment in relation to the individual body and situated within the "everyday" of larger social, cultural and political practices. In order to study the internet from this position, it is necessary to introduce a theoretical framework that describes the internet as spatial. This understanding is grounded in the fundamental concepts that space is both socially-produced and embodied.

Drawing from Lefebvre's seminal work *The Social Production of Space* (1991), we understand space not as a receptacle of social relations, but as dialectically physical, mental, and social. Lefebvre writes, "space is permeated with social relations; it is not only supported by social relations, but it is also producing and produced by social relations" (p. 286). Likewise, social space is the "space of social practice, the space of the social relations of production and of work and non-work" (1991, p. 225), so the unique character of a social space is shaped by the ways in which the body as a site of production, occupies space. Space is not just embodied, but "the whole of (social) space proceeds from the body" (1991, p. 405). Because space is dynamic, and not fixed or stagnant, it is also temporal. In his writing on rhythmanalysis (2004), Lefebvre proposes that spaces have rhythms. The body perceives and is affected by these rhythms through our five senses. The importance of this concept for this dissertation is that the illness disrupts the rhythms experienced by the body.

Building on her earlier work that uses a dialogical process of both social production and social construction of space to understand culture and political economy as spatialized, anthropologist Setha Low (1996, 2009, 2013) adds the concept of “embodied space.” This three-part framework allows us to understand the person as a “mobile spatial field -- a spatiotemporal unit with feelings, thoughts, preferences, and intentions as well as out-of-awareness cultural beliefs and practices” (p. 3 of unpublished manuscript) through which spatial construction and production are realized. Drawing from these conceptions, if the internet is both social and embodied, it is spatial.

The internet is produced by people in order to communicate with others, either indirectly (such as by conveying information via static webpages) or directly (via interactive communication such as email or social networking applications). In an effort to make sense of the internet’s digital form and our place in relation to it, we have thus far primarily used a spatial vocabulary. We describe it with terms such as 'navigate', 'site', and 'go to', to describe it and our interactions with it. This is logical, as we often understand our social relationships as part of a spatiality that is at once physical, geographical, and social. Internet social relationships and interactions, while altered by the medium in novel ways, are nevertheless enmeshed in our social world. They are relationships with people that we know are sitting at a computer or networked device in some physical location. Even the boundlessness that we may imagine being made possible by technology is against the backdrop of embodied spatiality. Whatever form social interactions take online, our cyborg, (Haraway 1991) selves are, in part, physical bodies that bring our embodied selves to the keyboard, to paraphrase Daniels (2009), and who talk, type, and create content on our mobile devices.

Rather than constructing a re-worked understanding of “the enmeshed, imploded, overlapping, interpenetrating nature of the physical and the digital” as Jurgensen (2012) has argued, spatial metaphors allow us to continue to conceptualize a medium which has come to be enfolded into our experience of the world and our understandings of social space. Smith & Katz (1993) argue that spatial metaphors should be subjected to periodic critical examination, and their context taken into account. Such an approach is particularly important during times of major transition, as the globalization made possible by technology has profoundly shifted our lives at all scales. The spatial metaphors that have been applied to the internet connote both boundedness (*chatrooms*; *websites*) as well as the boundlessness and temporality of mobility, connectivity and process. Using other conceptions of the internet as space, social theorists such as Castells (1996), Latour (2005), and Soja (1996) have used metaphors of flows, networks, and newly-shaped spaces to capture the alterations and disruptions of time, space, and scale that are the byproducts of globalization, of which information technologies and telecommunication are an integral part. For Haraway (1991), the image of a network suggests “the profusion of spaces and identities and the permeability of boundaries in the personal body and in the body politic. ‘Networking’ is both a feminist practice and a multinational corporate strategy” (p. 170).

Meyrowitz (1986) has argued that media alters our social relations by exposing us to other, previously hidden or inaccessible experiences, allowing us to blur traditional distinctions between gender, age, and authority. Drawing on Goffman’s (1959) metaphor of self presentation as drama, that is, a “front-stage” public self and a “back stage” private self, and McLuhan’s (1962) emphasis on medium, Meyrowitz suggests that the flow of information made possible through electronic media creates a transitional “middle stage”

that exposes the front and back to each other. More recently (2004), he writes that while there must always be a material local, media provides us with a “generalized elsewhere” with which to judge our local. As a result, local becomes more diluted and less important and media assumes some of our attention, commitment, and experience of what he terms “glocality.”

The more that our sense of self and experience is linked to interactions through media, the more that our physical locales become the backdrops for these other experiences rather than our full life space.” (p. x)

In writing about the mediating and reshaping effect that digital media has between locales and in experiencing our local, he does not take up the nature of the space created by the media itself. However, media as a mechanism of reshaping social relations is an entry point into examining how humans and technology shape each other, transforming not just social relations but what it means to be social.

In order to understand blogs as socially-mediated and co-created space through which bloggers narrate lived experience and navigate the complimentary and contradictory practices of patient-hood, it is useful to look at the political, social, and cultural conditions within which it is produced. The virtual has often been seen as distinct from the physical, and therefore, non-spatial. Such dualistic conceptions were particularly prevalent when the internet first came into widespread use, although they have persisted in popular as well as some academic literature. On the one hand, the internet has been conceptualized as a site of possible *liberation* from problematic social norms and power

structures (Herring et al 2004; Plant 1997)⁴ and potential stigmas of illness (Berger et al. 2005) via an un-mediated democratic, or even anarchic, realm where gender, race, class, body, and other identities are neutralized. By contrast, some have warned of a dangerous shift toward disengaging in “real” (i.e. face to face) social interactions and therefore diluting our most meaningful social relationships (Bauerlein 2009; Carr 2011; Keen 2008; Morozov 2011; Siegel 2008; Turkle 2012).⁵

Numerous scholars have criticized these perspectives as narrow and simplistic by demonstrating how they are rooted in outdated binary separations between person and body. Virtual space is shaped by and through multiple means, including the computers and devices people use and the physical infrastructure and informational tools that network them; as well as the embodied experience of people, the life experiences they choose to narrate, the social relationships they have offline and online, and the carryover between them. Both *through* and *by* blogging, my participants socially-produce and co-construct a

⁴ In fact, the technological developments that facilitate globalization, that are designed and implemented in the name of innovation and efficiency, break down labor into systematic parts, separating our thinking selves from our doing selves (Greenbaum 2004).

⁵ These claims have sparked numerous counter-claims that the networks we form online can *decrease* isolation, especially for certain socially and physically marginalized groups (Rainie & Wellman 2012). As the numbers of people using social networks has grown, the debate has taken to questioning the nature and quality of those social relations. For example, the phenomenon of Facebook, a social media network through which one can have (sometimes hundreds) of “friends” from numerous social realms collected in one place, has caused some to question whether social media actually makes us lonelier by encouraging narcissism (Lanier 2011). Others are concerned that users may fail to consider the potential consequences of “oversharing” private information publicly (Agger 2012; Albanesius 2010; Masum, Newmark & Tovey 2011), especially since it creates a permanent record. However, Burke, Kraut & Marlow (2011) and Cacioppo (2009) argue that social media is not deterministic of behavior, but can facilitate or exacerbate both social engagement and disengagement.

location in which they generate and participate in community across geographical and social divides.

It is important to look at who creates the tools and the potential effects they may have on user experience, as well as the larger structures that shape the creation of technology and which are reproduced through it, in order to better understand the context in which bloggers are writing. Bodker and Greenbaum (1991) have written that computer applications are socially constructed, "that is, designed by people, and not driven by some technological need" (p. 55). Arguments that the internet is a blank slate onto which individuals can map or shape their identities or onto which social, cultural, and political structures are simply transferred are rooted in assumptions of scientific objectivism that fail to recognize knowledge as situated and non-linear. Saskia Sassen (2002) describes the digital and the material as "imbricated" and writes, "digital space is embedded in the larger societal, cultural, subjective, economic, imaginary structurations of lived experience and the systems within which we exist and operate" (p. 368). It cannot, therefore, be considered un-mediated space. Likewise, the digital and the non-digital do not occupy exclusive realms, as the digital is situated in material practices and spaces.

Feminist scholars have explored the relationships between gender and digital technology and have argued that technology shapes us as we shape it. As Haraway (1991), famously wrote in *A Cyborg Manifesto* "...we are all chimeras, theorized and fabricated hybrids of machine and organism; in short, we are cyborgs." (p. 150). It follows that the creators of technology shape the framework for users, significantly influencing the many corners of our lives that are infused with technology. In the 1990s, fueled by enthusiasm about the liberating potentials of the internet, cyberfeminists critically examined the male

dominance of digital technological production and explored the potentials for women to create and shape it. In her review of cyberfeminism, Daniels (2009b) points out that while there is not and never has been *one* cyberfeminism, the range of theories, questions, and conceptions of how the internet can be and is used by self-identified women and girls is tied together by the common thread of a sustained focus on gender and technology. She argues that while some theoretical conceptions of the internet claim that it alter powers relations, identity, and embodiment, “the lived experience and actual Internet practices of girls and self-identified women reveals ways that they use the Internet to transform their material, corporeal lives in a number of complex ways that both resist and reinforce hierarchies of gender and race” (p. 101). I also found that the bloggers in my study revealed this complex constellation of practice and lived experience through the medium of blogging, my participants reflect and enact

Studying narrative

Studying narrative allows us to look at the “storied nature of human conduct” (Sarbin 1986), or, how people make sense of experience by constructing stories and listening to the stories of others. They also invite the narrator and the audience to challenge hegemonic structures. As Gabriel (2004) writes:

Narratives and stories enable individuals and groups to discover their voice, articulate their experiences and even shape their self-identities...storytellers and audiences are bound by a psychological contract ...[which] afford⁶ considerable

⁶ The term “afford” has special significance in Environmental Psychology as a fundamental concept of understanding the person-environment relationship put forth by J.J. Gibson (1979). His affordance theory describes how the physical environment and its objects can

authority to the person who speaks from personal experience...an authority which stands in direct opposition to the authority of the expert (p. 169).

More specifically, illness narratives privilege the voice of the individual patient, whose role in the medical relationship is usually overshadowed by the doctor's dominant position, thus challenging medical hegemony. Furthermore, focusing on women's illness narratives has:

...the potential of revealing alternate truths that expand traditional medical narratives since the way that women experience illness and medical treatment is very much dependent on broader social constructions of gender in society (DasGupta & Hurst 2007, p. 2).

Citing Nancy Mairs (1994), they add,

...expressions of illness are inherently political...since speaking about the female body, particularly a disabled female body, is breaking socio-cultural taboos of silence and secrecy around the feminine experience" (p. 15).

Precisely because illness narratives are *not* the voice of medicine (and its conception of illness as a disembodied, diagnosable, and treatable collection of symptoms), they are

"afford" various actions. For example, a tree can afford climbing, sitting under, leaning against, etc. The concept has continued to be applied mostly to the physical environment. The theory is useful for thinking about the environment as negotiable, but I argue two points: 1) there are other applications of the term and it is important to consider the context in which it is used. In the quote above, the author is not referring to narrative as a spatial practice, even though I will argue later that it is one; and 2) that environmental psychology has been overly-reliant on a concept that needs to be updated to incorporate a broader conception of environment and other kinds of affordances. In my earlier (unpublished) work, I applied the concept to physical objects used as therapeutic tools, naming them "emotional affordances." While this is not an attempt to build on the theory, it could most certainly be extended to consider the virtual (and situated) environment.

assertive and counter-hegemonic acts because they privilege the previously-under-represented or silenced voice.

Illness narratives deal specifically with the narrator's experience with illness or disease. In his seminal work, Kleinman (1988) writes:

The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in a meaningful way (p. 49).⁷

DasGupta & Hurst (2007) add that the illness narrative “does not merely reflect the experience of illness; it...[gives] coherence, symbolism, and meaning to what might otherwise have been a chaotic experience” (p. 1). Rather than a focus only on the narrative's purposeful outcomes, they focus on the meaning and possibilities of narrative and view it through a contextual, historical, and feminist lens. Women's illness narratives, they argue, are particularly important to focus on, given a long history of labeling women's bodies as weak and diseased, being controlled through structural and cultural mechanisms, and having voices and embodied knowledge silenced under the dominant medical paradigm. DasGupta & Hurst (2007) write:

Women's stories, like the stories of other marginalized communities, have the potential of revealing alternate truths that expand traditional medical narratives

⁷ Broadly speaking, an illness narrative can be written or told by anyone in relation to illness: the ill person themselves; family or friends closely affected by the illness; or practitioners writing about their work with illness. This dissertation focuses on narratives told directly by the ill person.

since the way that women experience illness and medical treatment is very much dependent on broader social constructions of gender in society (p. 2).

The illness narrative has the potential to restore agency to the disempowered person by asserting their voice and making public what was private. It rejects a dualistic conception of the body and challenges the more narrow and one-sided perspective of medicine. Ideally, it provides an opportunity to create greater understanding and build a better relationship between physician and patient by bringing in the patient's experiential knowledge, but this is not generally its primary aim. It places illness in the context of life, (relationships, environment, cultural, socioeconomic and political conditions, etc.) demonstrating that illness is experienced in a far more complicated way than a comprehensive set of symptoms. As public performances, these narratives seek connections at several junctures:

There is, throughout the history of women's illness narratives, the prevalent theme of connection, whereby the story of the individual experience is connected to a caring relationship, to family, and to community. In addition...there has also been the connection of one woman to public womanhood, an advocacy connection that sought to change the experience of many through the voice of one (DasGupta & Hurst 2007, p. 12).

In short, to privilege the "inside view" offered by illness narratives over the dominant view of medicine allows us to potentially see into the embodied experience of illness, or, as Katz writes, the "fleshy, messy, and indeterminate stuff of everyday life" (2004, p. x). It honors the ill person and her courage to publicly voice her experience of being in a vulnerable position. Reading or hearing narrative also allows the reader or listener to engage in "empathetic witnessing" (Kleinman et al 1997), which can facilitate

the shaping of a narrative to make sense of and give value to the experience. Frank (1997) writes, “one listens to ill people’s stories not in order to fix them by doing something ‘therapeutic,’ but rather to honor them” (p. 207). Telling these stories allows narrators and readers alike to feel less isolated in their private experience. And it allows us to challenge the detached dualism of the biomedical diagnosis in favor of a more holistic and authentically human portrayal.

As Haraway (1991) wrote, “cyborg writing is about the power to survive, not on the basis of original innocence, but on the basis of seizing the tool to mark the world that marked them as other” (p. 175). This study considers blogs written by women with illness as inherently feminist political narratives, but departs from the study of women’s illness narratives in significant ways. Like traditional oral and written illness narratives, these blogs give public witness to a story and can help the narrator make sense of life with illness. Unlike traditional illness narratives, which tend to be discrete, focused stories, these blogs document an ongoing life narrative, which is inclusive of and shaped by illness but not limited to it. The public and instantaneous nature of the internet requires bloggers negotiate their online voice to an audience in ways that are fundamentally different from oral narrative, for which the audience is live; or a written narrative, for which the audience lacks the immediacy and interactivity allowed by blogs. Furthermore, being online reshapes the context in which the narrative is written in novel ways, which I will take up later in this dissertation.

I argue that women choose to narrate their experience for a variety of reasons not limited to sharing their experience with illness. In fact, as previously mentioned, many of the bloggers in my study rejected the limitations of being labeled an “MS blogger.” They

saw themselves as writers and bloggers narrating their lives, not their lives with MS. Yet going online to find, connect with, and communicate with others who had MS was an important part of their motivations to start and maintain a blog. The participants in my study were part of a network of bloggers with MS, many of who located each other online and developed social connections based on a shared experience. I argue that the public-private nature of online narrative requires bloggers to negotiate writing to an audience that is virtual, somewhat unknown, and sometimes also physically present in their offline lives. I discuss blogging as situated in and reflective of larger social practices that shape gender and patient-hood, including dominant rhetorics. Finally, I demonstrate how blogging is part of a new cultural paradigm that both empowers and constrains individuals in their health care, and how new conceptions and practices of being a patient are created and reinforced by patients and the medical establishment alike through such online engagements.

CHAPTER 3: METHODS

Rationale for studying blogs

Personal blogs document the author's experiences and offer the researcher a window into those thoughts, as well as a location to study the practice of bringing those thoughts into the public realm. They create a historical, and if the blog is maintained, an ongoing record. In order to understand the perspective of bloggers with chronic disease, I conceptualize blogs as occupying three overlapping domains:

First, blogging is an intentional and active pursuit from which bloggers derive some benefit (Luik 2010; Stavrositu & Sundar 2008). Blogs are places to tell stories and the Internet allows bloggers to reach a wide and disparate audience almost instantaneously. It also dissolves geographical boundaries and allows people to seek out and find others whose stories are similar. In making connections, bloggers engage in a network with other bloggers whom they may not know personally, or may come to know online or, occasionally, offline (Miller & Shepherd 2004). This dissertation explores the nature of those connections that arise from the blogs and in discussion with other bloggers.

Second, a person who has a chronic illness, and who blogs about that illness, experiences that illness in two overlapping domains: the embodied and the digital. That is, they experience the illness's effect on their physical body and the physical realm of their world *and* they experience it through the act of writing about it in a medium that is intended to reach and engage with an audience across physical and geographical distance.

To explore these overlaps, I draw from theories that consider the interconnections between online and offline realms.

Third, blogs and other social media are included in a new cultural paradigm of health care that, as previously described, both offers opportunities for greater patient engagement and expects patients to actively participate in their care. Personal health blogs may reflect the extent to which patients engage in and negotiate some of these practices. I draw from theories that argue that these expectations are part of a neoliberal paradigm that emphasizes individual responsibility and I examine how lived experience enacted through online practices offers a more nuanced view of practicing patient-hood.

The internet as a location of study

Internet research is a relatively new and disparate field of study. It offers numerous opportunities to explore a social realm that has become interstitial in our lives, particularly in American society.

The profound alterations the internet and social media have made in Americans' daily lives are just beginning to be studied, including the significant use of the internet to gather health information. According to the Pew Internet and American Life Project (Fox 2011), 78% of American adults go online. Of this group, 60% gather health information and 20% have gone online to find others who might have health concerns similar to theirs, many accessing social media related to health. However, chronic disease can be a roadblock to these activities because fewer adults with one or more chronic illnesses go online (62%

compared to 78% of the general population). While their use of the internet is lower overall, these users are more likely to contribute to and consume user-generated content related to health than people without chronic disease, suggesting that seeking information and connections with others around health issues is particularly important for those with chronic disease.

People have gone online to share health information since the internet first became widely available to the general public. Initially, online group interaction took place primarily through listserves and other forums that allowed people to communicate through messages and discussion threads (Rheingold 1993). In the 1990s, Other information was shared on static websites, where interactivity was not possible. Now, Social networking sites create myriad ways to connect and communicate with others with similar interests. 'Blogs' (originally called 'weblogs') were among the first social media applications. Blogs are websites that contain a series of often updated, reverse-chronologically ordered posts, usually written by a single author (Hookway 2008). They commonly include archives, a blogroll (a list of links to other blogs), and a reader comments section. While they previously required knowledge of computer programming to create, several free, user-friendly software programs such as Blogger and WordPress make them easier to produce and maintain. While they are interactive in that readers can often comment on a post, they are primarily written from a singular perspective. Initially most blogs were written by individuals, but as they have become widespread, they are also written for numerous commercial, news, and organization websites, and may be written by more than one author. The growing popularity of "micro-blog" applications like Twitter and Tumblr, especially among younger internet users (Brenner 2012), demonstrates that

there is no singular definition for blogs and that there is much overlap among social media applications (boyd 2006). Likewise, the increased use of mobile technologies like smart phones and tablets favors shorter, more frequent communication than blogs usually provide. However, this dissertation focuses on journal-style blogs written by individuals, which typically have longer narrative structures and may be less likely to be written and read on mobile devices.

Measuring the size and influence of the 'blogosphere' is virtually impossible given the decentralized nature of the internet, but the scale of it and its significance in the cultural landscape make it an important area of study and a rich source of data. Some systematic efforts have been made to identify trends. An estimated 12 to 25 million American internet users write blogs (Miller & Pole 2010). According to the 2011 annual survey by Technorati.com, which surveys a sample of English language blogs, 60% of blogs are written by Hobbyists (as opposed to professional bloggers or those who blog about their industry or business). About three out of every five bloggers are male. The majority of bloggers are aged 25-44 and are more affluent and educated than the general population. According to their survey, the top reasons that people write blogs include sharing experience and expertise with readers; speaking their mind on areas of interest; being involved with interests they are passionate about; and meeting and connecting with like-minded people. Of interest to this study, health was among the top 30 tags (or searchable keywords) and a 2006⁸ study estimated that at that time, bloggers who focused specifically on health issues made up only about 2% of blogs (Lenhart & Fox 2006).

⁸ Most recent data available for a comprehensive estimate of internet blogs.

Gender differences in blogging behavior and inequalities in recognition of blogs have been well-documented (Herring et al 2004; Pedersen & Macafee 2007; Ratliff, 2004, 2006). It has been shown that despite the large numbers of women bloggers, who also tend to write more and maintain blogs longer (Henning 2003), blogs that are considered the most *influential* by marketplace standards are written by white American males. Pedersen and Macafee (2007) note that multiple factors contribute to a misrepresentation of the 'blogosphere' as being male-dominated, and help to reproduce problematic gender norms on the internet. These factors include differences between subject matter that men and women write about that yields uneven search engine results (for example, men tend to focus on politics or technology, while women focus more on personal experience); differences in efforts to market their blogs; problematic standards of measuring "influence;" and uneven attention from the mass media.

The blogs I examined were journal-style, not easily found through web searches, were linked to a small number of similar blogs, and were therefore not considered "influential" in the market-driven use of the term. However, as Pedersen and Macafee (2007) attest, that terminology can be questioned. While the blogs in this sample occupy a tiny corner of the blogosphere, they are significant to bloggers and readers and are well worth studying what might otherwise be overlooked. Also, as mentioned previously, this dissertation focuses on women's voices online, in order to hear the voices of patients who are often overlooked.

Why study blogs?

Miller and Pole (2010) call blogs the "quintessential Web 2.0 application" (p. 1514) and credit the user-generated content characteristic of an interactive online environment with being responsible for the rapid growth in health-related content online. As such, blogs are a unique and important site through which to examine intersections of health, gender, and engagement with the medical establishment, from the perspective of individual patients. However, studying the 'blogosphere' can be difficult. Herring (2010) claims that "the full extent of the blogosphere is nearly unmeasurable" (p. 244) due to the decentralized nature of the Internet. While there are numerous blog-hosting platforms (like Blogger and WordPress) they are by no means the only locations for blogs. In addition, the high rate of blog creation and abandonment, the existence of private blogs, and blogs in other languages that are not indexed by English language search engines, make the search even more difficult. Also, it can be difficult to distinguish between blogs created and maintained by individuals and ones created by corporations or organizations that include posts written by self-identified patients. These factors make random sampling of a specific type of blog impossible. Nevertheless, a few systematic efforts have been made to accurately capture the blogosphere (Lenhart & Fox 2006, Herring, 2010, Hookway 2008).

Specific to health-related blogs, Miller and Pole (2010) conducted a systematic search of the most influential health-related blogs with a US-focus.⁹ They identified 951 blogs and examined the content of the blogs and blogger characteristics, such as demographics (gender, age, education, employment) and the orientation of the content,

⁹ Their study only attempted to identify health blogs appropriate to their study, not estimate the number of health blogs in general or compared to other types of blogs.

such as professional, personal, or informational. More than one third of the total sample (37.7%) blogged from the perspective of a patient consumer and two-fifths of the total sample (42.6%) focused their blog on his or her experience with a particular condition.

Ethical considerations in conducting research online

As with any research, ethical practices need to be considered (Robinson 2001; Sixsmith & Murray 2001). Because the Internet is a relatively new field of study, fewer standard practices are established for protecting human subjects. Also, the nature of the Internet opens up new perspectives and arguments for methodological and ethics approaches. Debates over concerns about user privacy are ongoing in both popular media and academic research (Albanesius 2010; boyd 2013; Kaironz 2011; Woo 2006; among many others). Researchers must also consider whether their practices may be exploitative in any way. Researchers can also use many of the strategies used by advertisers and other commercial entities to locate users, analyze behavior, and aggregate data. Using them for academic research may be no less nefarious than private interests.

Hutchinson (2001) outlined three schools of thought about using personal online content for research without permission, even when it is publicly-accessible: 1) publicly available information is public and therefore should be able to be researched without explicit permission (Sudweeks & Rafaeli 1995; Walther 2002); 2) personal information, such as blog entries and comments, while public, are personal and should be treated as private (Elgesem 2002; King 1996; Scharf 1999); 3) the Internet is "publicly-private and privately-public" (Waskul and Douglas 1996, p 131) and should be treated with a balanced

approach. While a conservative approach may be warranted by some studies, there is a strong argument for blog research to accept the premise that blogs are a public act of writing for an implicit audience (Hookway 2008). After reading the blogs, I determined that content of this specific type of blog, while personal, is intended to be read by a wider audience. In addition to documenting their personal experience, bloggers wrote about Multiple Sclerosis advocacy efforts, and shared experiences and advice. Furthermore, readers frequently commented on the blogs and sometimes bloggers responded to them directly, indicating their engagement with a public audience. Nevertheless, I protected any non-public information I learned about my participants. The specific methodologies are discussed in this chapter.

Institutional Review Board (IRB) considerations

Because these blogs are publicly-available documents, bloggers were not asked if I could include their blog in the Phase 1 sample. Also, having established the blogs as public sources of information, I made use of publicly-available contact information or mechanisms to reach the bloggers to recruit survey participation for Phase 2

For Phase 2, the Internet-based survey, the subset of participants were anonymous and their identity was protected. They were asked to provide an email contact only if they were interested in being contacted for further participation.

For Phase 3, the discussion between participants, took place on a password-protected website to which only I, my advisers, and participants had access. Participants chose their own username, which is how I identify individual participants in this dissertation. It was

made clear in the consent form that they should choose a username they would not mind having attributed to them, and I reiterated this during the consent process. These usernames are never explicitly linked to the names of or the URL for the blogs studied in this dissertation. Finally, once the discussion concluded, the forum was deleted from the website.

Three-part methodology

I narrowed my research down from an initially broader interest in studying the embodied experience of illness and the phenomenon of social media as part of contemporary patient-hood. Prior to the start of in-depth research, I explored the online presence of a number of “types” of illness, including terminal, mental, and chronic illnesses. I found that numerous specific illnesses are represented on many social media platforms. I chose to focus on chronic illness because, while any illness requires a person to negotiate its role in their daily lives, most chronic illnesses are not curable and are experienced in a different way than terminal or mental illnesses. These othwe types of illnesses may, or may not be, curable, have different prognoses, and are experienced differently than chronic illness. With terminal and other life-threatening illnesses, the focus is often on being cured. With mental illness, which can be chronic, the primary focus is usually on the psychological experience rather than the physical. While people with chronic illness are also concerned with a cure, they also must negotiate a disease they will have over a lifetime.

As previously described, I chose to study MS specifically because it is a disease that that presents with a wide variety of symptoms, affects people with the disease in different ways, and often fluctuates in severity over the life span. The disease affects women 2-3 times more frequently than men and thus lends itself to privileging women's voices specifically. Also, there is a small, but active blogging community that provided a rich source of data.¹⁰

Research phases

The research consisted of three phases. I describe the phases briefly here, and describe the sampling strategies and data analysis later in the chapter.

*Phase 1. An ethnographic content analysis of 40 blogs written by women with MS.*¹¹ This analysis allowed me to capture an overall picture of the blogs, that is, who was writing and what they were writing about. To build on this, I designed the two phases that followed to capture more detailed data about the bloggers themselves and their perspectives by engaging with them directly.

Phase 2. An online survey. I sent an anonymous online survey to all 40 bloggers from Phase 1 and received 20 responses (a 50% response rate). The survey allowed me to understand participants' blogging practices and the role blogging played in their lives. The

¹⁰ While I do have a close family member with the disease, I don't believe it had a direct bearing on my choice, other than making me somewhat more aware of it than other chronic illnesses. Prior to this research, I knew little about the disease, nor did I speak with this family member about it. The variability of the disease has made it an interesting case study to observe the similarities and differences among my participants.

¹¹ I chose to study 40 blogs because while there is no way to determine how many blogs there are that fit my criteria, my search yielded the same blogs again and again, and I found similar themes among them, so I was confident that I had collected a fair representation.

survey asked respondents to provide an email address if they were interested in further participation and 17 of the 20 opted to do so.

Phase 3. An online discussion forum. The discussion allowed me to directly solicit the perspective of the bloggers and provided them an opportunity to connect directly with other bloggers. Three overlapping themes were explored over the course of the discussion: 1) being a part of the MS 'blogosphere' and feelings of connection to other bloggers; 2) expectations of patients by the medical establishment to be 'participatory' patients; and 3) the blend between their online and offline lives. I chose to conduct a discussion online in order to reach a broad geographic sample and in order to have bloggers discuss these themes in depth with each other, with as little prompting from me as possible.

Sample and sampling strategy

The sample and sampling strategy for each phase is described in detail below.

Phase 1: Ethnographic content analysis

The blogs for the ethnographic content analysis (Altheide 1987) (Phase 1) were chosen based on the following criteria:

- Written by one author, a woman who identifies herself as having MS and who writes, at least partly, about her experience with the illness.
- Written by a person living in the United States or with a US-focus, because I was interested in looking at patients' experiences with the American medical

establishment.¹²

- Had been created at least 6 months prior to the start of data collection. A blog with at least one post within 6 months of the start of data collection was considered up-to-date based on Miller & Pole's (2010) criteria.
- Located through a general Internet search engine (such as Google and Bing) or through a link from someone else's blog, generally a "blogroll," which is a list of other blogs the blogger recommends to her readers.

I identified blogs in two stages. First, I conducted general keyword searches in Google and Bing search engines and identified some blogs that fit my criteria. Because the searches brought up more unrelated than related websites, this was not an efficient or effective way to complete a comprehensive search. Once I had identified several that fit the criteria, I developed a snowball sample from blogrolls. I then visited each linked site to determine if it fit the criteria. Many of the blogs linked to each other and to the same blogs, so I continued this practice on each blog until I reached saturation. I eliminated blogs that were clearly inactive (i.e. showing an error screen) as well as blogs that had not been updated in more than 6 months. I further eliminated blogs that were not primarily narrative-based descriptions of their lives, such a blogs that only featured videos, or blogs that were primarily a record of the bloggers' medication or diet.

Once the list of active blogs meeting the criteria had been selected, I identified and

¹² I mistakenly included a blogger from the United Kingdom, who participated actively in the discussion. Her perspective as a patient in a very different health care system turned out to be an important discussion topic as it prompted participants to compare experiences.

tracked blog characteristics, including descriptive statistics such as the number of entries and the age of the blogs; and any general personal and demographic information about the blogger that I could glean from their user profiles and self-descriptions. I also took note of visual elements, such as color and design schemes, graphics, images, and video. All of this information was recorded on a schema I created in an Excel spreadsheet (see Appendix VII).

I read each blog in detail over the course of three months (January-March 2012) and took extensive field notes. I chose one entry from the month of February and one entry from the month of March from each blog for further analysis. One of the two entries was either written on February 7th or I used the post immediately prior to that date. The second of the two entries was either written on March 7th or I used the post immediately prior to that date. On a few blogs, the most recent entry was before February 7th, so I only used that post. I chose these two dates to be somewhat representative of an average day, as neither date were significantly close to any major holidays or events.¹³ In total, I analyzed 68 posts.¹⁴

I created a separate document for each blog and copied and pasted the two entries into them. I then re-read the entries and took further notes. I uploaded each document into

¹³ While Valentine's Day did fall within this time frame, I chose the February date to be before it, and the March date to be several weeks after it. It was only written about in a few entries.

¹⁴ I did not code and analyze comments left by readers on the blog. While they provided some useful insight, comments are not a representative source of information, because they are posted or allowed to be posted at the discretion of the blogger, and because the small number of comments, often made by the same few readers, cannot be seen to represent the viewpoints of the much larger pool of readers.

QSR NVivo 9 qualitative analysis software program¹⁵ and conducted a thematic analysis of the text. This is further described below.

Phase 2: Online survey of bloggers

I conducted the survey to get an overall sense of why they blog, their daily practices of blogging, and how they see it fitting into their lives. This was a useful way to build on the ethnographic content analysis and to gather specific demographic information. The survey [see Appendix III] consisted of twenty-two questions, with two prompts for sub-questions. About half of the questions were multiple-choice and half were open-ended and asked about why they blog, what they blog about, their interactions with and connections to other bloggers, and basic demographic questions about themselves.

I first created a draft survey using the SurveyGizmo software platform and piloted it with one blogger, who blogs several times each week and who writes frequently about health policy, medical research, pharmaceutical companies, and media coverage of MS. She also frequently features what she calls the “Carnival of Bloggers” for which she re-posts recent posts from other MS blogs. Her blog served as an excellent starting point since she was clearly, as she described in the pilot survey, a “leader” in the MS blogging community and her blog lists numerous resources and links to other blogs. Her feedback prompted me to modify questions, particularly multiple-choice questions to offer more or different

¹⁵ QSR NVivo 9 is a qualitative analysis software program that allows the user to import texts, images, video, and other qualitative data into a central repository. Users can then organize, code, and analyze data using a variety of features including coding and thematic schemes, and keywords searches.

answer options. Having this feedback improved the quality of my survey and allowed for more detailed and focused answers. Because her participation was part of the survey development and I made significant changes before sending it to the larger sample, I did not include her responses in my overall sample. She did not respond to my request for her to take the final version of the survey.

Once the survey was ready for distribution, I identified the contact information for each blogger. On 29 of the blogs, they provided their email address somewhere on the blog or provided a contact form I filled out. For the remaining eleven blogs, however, gathering contact information was difficult because it was not provided anywhere on the blog. For these, I reached out to them via a number of methods. I sent a message via Facebook to one blogger. One blogger wrote for the health websites HealthCentral.com and I contacted her via a private message on the website. For the remaining nine bloggers, I posted a comment to their blog. If comments were moderated (i.e., comments were viewed by the blogger before being posted), I explained why I was reaching out and that the comment was not intended for publication. If comments were not moderated (that is, they were posted immediately to the blog), I likewise made my purpose clear and advised that they erase my comment once they read it.

I sent all of the bloggers (N=40) a recruitment email (see Appendix IV) containing a link to the survey. I received 20 full responses and there were 9 abandons (meaning that a participant opened the survey but did not complete any of it). The survey was available for a period of four weeks before I closed the survey. The survey was anonymous, but respondents were asked to provide their email address at the end if they were willing to be contacted for further participation. Although the survey was anonymous, I was able to tell

that most of the responses came from participants I had been able to contact directly via email (none of the bloggers were previously known to me). This was clear because I sent the survey first to those bloggers, then to other bloggers via other methods as I tracked them down. The majority of the responses came shortly after the initial email and I recognized many of the email addresses they provided.¹⁶

Once I closed the survey, I generated a final report using SurveyGizmo, which provided descriptive statistics and grouped the answers to open-ended questions. I created a separate document for each of the open-ended questions and collected all of the answers to that question. I then uploaded the documents into QSR NVivo 9. I will report the findings of the study, including demographic information in the next chapter.

Phase 3: Online discussion forum

I included this more participatory phase in the study in order to solicit bloggers' perspectives directly, as well as foster a discussion among themselves. While I posed three sets of questions throughout the 5-week period, I encouraged participants to ask their own questions and bring up new topics.

Of the 20 survey respondents, 17 provided their email addresses for follow up. I sent an email explaining the purpose and terms of participation [see Appendix IV] for this phase and asked them to respond via email if they were willing to participate. Eleven bloggers

¹⁶ In future research, it may be better to identify the direct contact information of a blogger before deciding to include their blog in a sample. This might improve a response to further participation.

wrote back saying they would participate, but two dropped out before the discussion began, leaving nine participants. In order to keep their identities confidential, I asked them to choose their own username, with the understanding that if I were to cite them in this dissertation, it would be the name that I use for them. I also asked them to write back explicitly stating their consent to participate and received responses from all of them.

The discussion was launched in mid-April 2012 and lasted for five weeks.¹⁷ Originally, the discussion was scheduled to last for three weeks but the conversation was very active and I wanted to allow enough time for topics to reach a natural point of transition. At three points during the time period (roughly a week and a half apart), I started a new thread and wrote a brief introduction to the topics and asked [new] discussion questions. When I posted, I also sent a separate email to alert them that I had done so. After the first week, I asked participants for feedback about the format of the message board and welcomed suggestions for improvement. I followed the discussion daily, but only posted a few times, such as brief welcome messages or responses to direct questions or statements, and at twice to ask probing questions.

Initially, I had designed all three sets of questions ahead of time. It was clear from the

¹⁷ Setting up the discussion forum took more time than I had anticipated, so the start of the discussion was delayed by two weeks. The primary reason was that I originally planned to host the forum on a password-protected section of my personal website collettesosnowy.org, which is a WordPress blog hosted through OpenCUNY.org, an open-source platform run by and for students at the Graduate Center of the City University of New York. Adding my participants as users to my website quickly became cumbersome due to the design of the platform, which is not intended to be a social networking site or to include participants from outside of CUNY. I opted to move the board to the forum-hosting website proboards.com, which allowed me to create a password-protected board that blocked any content from unregistered users. Once I set up the board, participants created individual accounts with their preferred username and I provided the password to the board. This process went fairly smoothly and only two of the participants needed any assistance.

open-ended questions on the survey results, that I did not need to spend as much time “warming up” as I had anticipated, because bloggers were already answering the more complex questions I had prepared for the discussion. I was eager for them to start conversing with each other, so instead of asking them to provide a more detailed introduction and tell their stories, I asked them to introduce themselves briefly and started right away with the more substantial questions. This first set of questions pertained to their perspective on being bloggers and what sense of connection they feel to others, either through blogging or elsewhere.

Likewise, the discussion from the first week prompted me to modify the questions for the second and third weeks, which I saw as too repetitive for such a dynamic group. In the third week, I asked more abstract questions about where they saw blogging and being online overlapping with their off-line lives, in what setting and circumstances they blog, and topics they purposefully avoid on the blogs. I began wrapping up the discussion after four weeks, and the last week consisted of bloggers posting short comments and sharing the names and URLs of their blogs.

There was active participation on the board throughout the collection period. The participant who was most active posted 23 times, while the least active participant only posted four times. Other participants posted 7, 8, 8, 9, 14, 15, and 18 times respectively. The four bloggers that were the most active guided and shaped the discussion more than other participants. Participation began to slow after the third set of questions, so I decided to formally end the discussion, although I offered to leave the board open for them to continue talking to each other without my intervention if they wanted to. Several said they were sorry to see the discussion end and while a few expressed an interest in continuing,

one participant said that she didn't think the discussion would last without my lead. Another participant started a Facebook group for MS and invited the others to join.¹⁸

Coding and data analysis

Rather than beginning from a position of pre-established concepts or themes, I used a grounded theory approach (Glaser & Strauss 1967). This bottom-up approach allows hypotheses, categories, and conceptual codes to emerge from the data collection and analysis, rather than impose a more rigid top-down structure of analysis. Sampling was aimed toward theory construction, not representativeness. My codes for analysis were developed after I conducted a close reading of the data from all three phases (content analysis, survey, and discussion), during which I took detailed notes on recurrent patterns, themes that had shaped my inquiry, unexpected themes, and outliers.

I chose to code the texts (blog posts, answers from open-ended questions on the survey, and the transcript from the discussion) all at once, rather than separate them by phases. I did this so that I could begin to see patterns and overlap among the texts right away. I analyzed data using the method of "open-coding" followed by "focused-coding" (Charmaz 2006). This strategy allowed me to first group and categorize data based on the major themes that had arisen from my reading, such as physical symptoms or engagement with the medical establishment. I could then identify recurrent patterns, as well as more

¹⁸ The Facebook group was open to other users of Facebook, not just the participants in my study. I did not follow up on this group primarily because it was not in the scope of my study and because I didn't want to join the group in case my role as a researcher was problematic. I also wanted to maintain some distance from my participants and I have personal content on my Facebook account.

detailed sub-themes emerging from the texts, such as a specific focus on neurologists and bloggers' experiences with the MS Society. Because there was significant overlap of themes and sub-themes between the three phases, this strategy also allowed me to see areas of crossover.

Once the discussion was closed I read carefully through the written text, taking note of major themes, many of which were consistent with themes from the blogs. I then uploaded the written transcript of the Phase 3 discussion to QSR NVivo 9 analysis software, with each "week" (i.e. set of questions and subsequent discussion) as a separate document. Having read the texts from all three phases, I created a coding scheme to be used consistently across all of them. I coded them together in QSR NVivo 9. The final coding scheme was grouped as follows:

"Physical" (i.e. symptoms, the body, medication and treatment, etc.)

"Emotional" (i.e. references to emotions, feelings about having MS, etc.)

"Interpersonal" (i.e. relationships with others, how other react to them, etc.)

"Blogging" (i.e. discussion of blogging practices, thoughts about blogging and being a blogger, etc.)

"Medical Establishment" (i.e. interactions with providers, insurance coverage, etc.)

"Interests" (i.e. descriptions of everyday life, social activities, travel, things they like to do, etc.)

"Work and Financial Support" (i.e. employment or former employment, benefits like disability and SSI, how they support themselves financially, etc.)

“Descriptive Language” (i.e. metaphors, poignant writing, etc.)

“Activism and Advocacy” (i.e. political activity, fundraising, outreach and education, etc.)

“Images” (I gather all images that appeared in the blogs in one category. There were no images from the survey or discussion)

I then read the text under each node to identify sub-themes and topics. The QSR NVivo 9 software allows sources to be coded in multiple ways and under multiple coding categories. This allowed me to see the many areas of overlap between texts and within texts.

The descriptive statistics from the survey and schema were not coded but were looked at in depth for patterns. Having described the goals and design of the three individual phases, the sample and sampling strategies for each phase, and overall data analysis, I outline the findings in the next chapter.

CHAPTER 4: OVERVIEW OF FINDINGS: THE BASICS OF BLOGGING MS

This chapter introduces the study's findings and offers a portrait of the bloggers, giving an overall picture of who they are and why they blog. I also describe the medium of blogging by giving an overview of the blogs, including their visual and functional elements.

Characteristics of the bloggers

Demographics I gathered demographic information about bloggers both from the content analysis (Phase 1) and the survey (Phase 2). From Phase 1, I was able to get a general idea of who the bloggers were and discern the kind and amount of information they shared about themselves. From the Phase 2, I was able to gather more consistent results and generate descriptive statistics. All of the bloggers were white, and most were middle-aged,¹⁹ highly-educated,²⁰ and living in suburban areas across the United States (with one blogger from England).²¹ Most reported that they were married, widowed, or divorced; about half had children and grandchildren. More than half were not working due to a disability, while a few worked full or part time, two were retired, one was a full time student, and one a stay-at-home mom. The length of time they had been diagnosed with MS ranged from a few months to 30 years.

¹⁹ Ages ranged from 24-76 years, with the majority between 34-57 years

²⁰ All had at least a high school diploma; all but two reported some level of higher education, ranging from some college courses to a Ph.D.

²¹ While this blogger was included in the sample by mistake, but by the time I realized it, she had agreed to participate in the discussion. I chose not to exclude her and her perspective offered some interesting comparisons between the health care systems of the US and the United Kingdom.

The disease is most prevalent among white women and the onset generally occurs in early middle-age, so while the age and race demographics of my sample are consistent with the general profile, other factors, such as education are likely more reflective of who blogs, which begs the larger question of health disparities and unequal access to resources, which I will take up later.

Public presentation The extent to which a blogger provided personal information about herself suggested varying levels of concern for privacy. In general, bloggers wrote quite openly about their lives, and most posted pictures of themselves, gave at least their first name, and provided some details about themselves such as where they lived, marital status, etc. However, there were some who reported little personal information, such as a profile or biographical description, yet wrote very openly about their daily lives, suggesting that they felt more comfortable sharing their intimate experiences and thoughts if they felt they could protect their personal identity.

Characteristics of the blogs

I looked for common characteristics and patterns of the blogs in order to analyze them as a whole. I tracked characteristics of the blogs using a schema (see Appendix VII.) that included elements such as a blogroll (a list of links to other blogs); an archive of posts showing the number and frequency of posts; visual elements, such as layout and design, advertisements, and graphics; and links to other social media applications such as Facebook, Twitter, and Google Plus. All of the blogs were journal-style and focused on the blogger's daily life, as per my criteria in selection. A few of them were explicitly geared

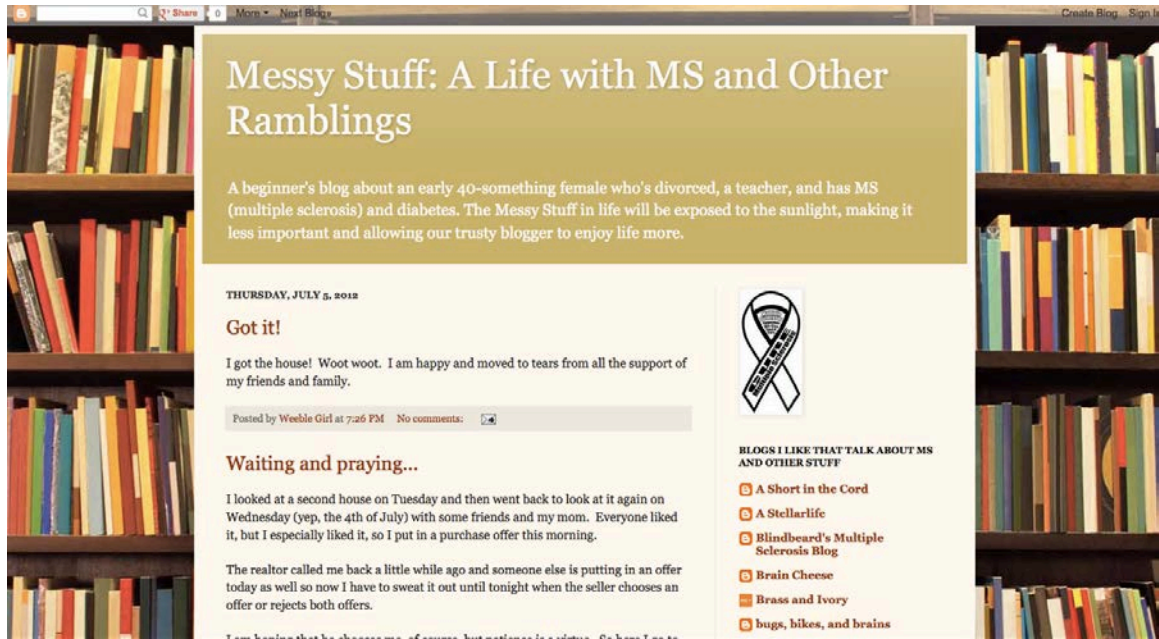
toward educating readers about MS and reporting current developments such as medical research findings and policy conferences. Bloggers that did not focus on education, advocacy, and medical research, did write about these topics from time to time but in ways that were more integrated into narratives about their everyday lives.

Software programs The software program called Blogger²² was the most commonly-used blog-hosting platform.²³ While this dissertation is not focused on software design and capabilities or a visual analysis, a general overview of the functions and features offer insights into some of the choices bloggers make in designing their public profiles. The Blogger software platform offers hundreds customizable templates, backgrounds, and features, and none of the blogs in my sample used the same template. However, certain basic functions were built into the platform as options and were commonly used. These included a biographical profile, a blogroll, an archive of blog posts dating back to the first entry and organized by month and year. Posts could also be tagged, labeled, or categorized using keywords. A few (7) blogs featured paid advertisements, and several had a feature that identified the geographic area of people who had recently visited the site.

Fig. 1

²² One of the functions of the Blogger software program is that it identifies similar blogs within the network. This might influence which blogs the bloggers in my sample find and choose to include in their blogrolls. Since my primary recruitment method was a snowball sample through blogrolls, it is possible that blogs hosted on Blogger may be over-represented in this study.

²³ Three blogs used WordPress and one blog used a platform hosted by an internet service provider in her local area.



The example above (Fig. 1) shows a typical front page of a blog. In this case, the title block includes a brief description of the blogger and the general focus of her blog. Posts, two of which are visible here, are presented in reverse chronological order and are usually dated (in this case, only the most recent post is). In order to comment or view reader comments, the reader has to click on a link below the post. To the right is a “blog award” (described below) and a blogroll. The following section describes and shows examples of other common blog elements.

Interactivity Opportunities for public interactivity on a blog are more limited compared to newer social networking applications like Facebook and Twitter, where interactivity among users is a primary feature. While personal blogs are characterized by one dominant voice, comments on blog posts, blogrolls (Fig. 2), and “blog awards” from other bloggers (Fig. 3) are the primary modes of interaction between bloggers and readers. The ability for a reader to comment on a post is the most interactive feature of a blog

because it allows direct engagement by readers and a forum for brief conversation between readers and/or between readers and the blogger. The vast majority of blogs in the sample allowed comments.²⁴ A second means of interactivity between bloggers was to link to each others' blogs through blogrolls. As evidenced by my snowball sampling technique, there was a network of links between many of the blogs in my sample. A third means of interactivity between bloggers was "blog awards." These appeared as graphic, usually listed on the sidebar of the blog. This was a feature of the Blogger software program and awards such as "Prolific Blogger Award" or "Beautiful Blogger Award" (See Fig. 3) were "given" from one blogger to another. In some cases, commercial health websites, such as Wellsphere.com, gave awards that specifically identified the blogger as an MS blogger.

Fig. 2



Fig. 3

²⁴ Comments could be moderated, meaning that the blogger has to approve comments before they are posted, or unmoderated, meaning that the comments are immediately made public, although the blogger does have the ability to take them off after they are posted. Of blogs that allowed comments, about half were moderated and half were unmoderated.



Titles of the blogs The titles of the blogs (Appendix I; Fig. 4 example) indicated certain narrative styles and purposes by making explicit reference to MS, chronic illness, or disability; and/or using metaphor, humor, and/or language that described an attitude or outlook on their life. The most obvious indication that their blog focused on MS (or, relatedly, chronic illness or disability) was if they used the words “MS” or “Multiple Sclerosis” in the title. Most of these titles indicated the role MS plays in daily practice, incorporating terms such as “living” or “life” and “journey” or “path.” Some titles used metaphors for effects or symptoms of the disease, such as “Turtle Speed,” which referenced the fatigue many people with MS experience and the need to pace themselves. Many titles used humor or light-hearted language, such as “Funky Mango's Musings.” Finally, some blog titles conveyed a strong attitude or outlook, such as optimism (“Stuff Could Always Be Worse,” “Sunny, With A Chance of Clouds,” “MS~LOL: Multiple Sclerosis a Life Of Learning,” “Life Can Be Simple” “A stellar life”); or activism or rebelliousness (“disAbled in San Francisco,” “X-out MS,” “MS Renegade”).

Fig. 4



Photos Bloggers often included photos in their blog posts. These included personal photographs, such as photos of family members, friends, pets, and themselves; and artwork or crafts made by the blogger. Other images were stock photographic images (like a light bulb to symbolize an idea, and a “Don’t Walk” signal in reference to problems with mobility) or images that the blogger altered with text. Some photos were taken from another source, such as a still from a video or a political speech or a newspaper photograph.

Patterns of blogging

In order to assess the role blogging plays in their daily lives, I tracked several patterns from the content analysis and the survey. Using the archive list for each blog, I counted the total number of posts from the blog’s first post up to December 31, 2011. The mean number of blog posts was 281 and the median was 101. The number of posts per blog ranged from 0 to 2,160.²⁵ The age of the blogs ranged from December 2005-February 2012

²⁵ The two blogs that had no entry as of December 31, 2011 were included in my sample because they posted during the collection phase for the ethnographic content analysis (February-March 2012). Also, seven blogs did not have an archive of blogs. Because manually counting was impractical and prone to error, I did not count the number of entries, but did ascertain that the number of entries was within the range.

(the cut off date of the first phase of my study). Most blogs in the sample were created in 2008 (n=9) and 2009 (n=7). There was no correlation between frequency of posts and the age of the blog, and the frequency and consistency of posting varied widely.

The survey (Phase 2, N=20) captured information respondents provided about blogging practices and patterns. Significant results were as follows:

1) Blogging is a regular practice in their lives. On average, most respondents reported posting a few times a month (N=9), followed by once a week (N=4), a few times a week (N=3), and daily (N=2). No one reported posting every few months or longer.

2) Bloggers invest time in writing a post. On average, most respondents reported spending more than an hour (N=7) writing a post, including preparation and research if it was relevant, followed by less than 30 minutes to an hour (N=5), and less than 30 minutes (N=4).

3) Bloggers read other blogs about MS. Most respondents reported reading other blogs about MS often (N=13) or sometimes (N=6).

4) Comment activity varies. Almost half of the respondents reported that they never comment on other blogs about MS (N=8), while almost as many reported that they sometimes (N=6) or often do (N=6). Most reported that readers sometimes comment on their blogs (N=8), followed by often (N=6) and rarely (N=5).

5) Bloggers do participate in other online social networks related to MS, but not frequently. Most answered that they rarely post to other MS-related websites such as discussion forums and social networking sites (N=7), followed by once a week (N=5), and occasionally (N=4).

Content analysis of blog posts

I coded and analyzed the text and images from selected blog posts (one or two posts per blog, as outlined in the methods chapter) using the coding scheme I had created. Below I describe some of the major findings, which I discuss in greater detail in the next two chapters.

Physical aspects of the illness Not surprisingly, bloggers wrote most frequently about their physical bodies. Of course, in writing about their lives, most journal-style bloggers inevitably write about their physical reality and embodiment, but as this study looks at women's lived experience with chronic illness, the physical dimension has an added layer. I paid particular attention to the physical realities directly associated with having MS and how bloggers wrote about negotiating everyday life. The most common physical limitations they described were fatigue and disability – primarily physical disabilities but also cognitive problems such as memory loss.

Bloggers wrote frequently about negotiating their daily lives with fatigue. One blogger reported on a 2011 survey by the Multiple Sclerosis International Federation that found that 86% of respondents reported fatigue as one of their three main symptoms. Bloggers wrote about rationing their limited energy, knowing that if they pushed themselves too much it could have the negative consequence of being too tired to do anything at all. After pushing herself too far, one blogger wrote “someone without MS would have been exhausted and stupid for doing what I was doing. With MS I really put myself in a bad situation.” Illustrating the pervasive yet unpredictable effect the disease can

have on everyday life, one blogger who is working toward her college degree described how she and a professor had spent a lot of time planning a field trip that wouldn't require too much walking, but the sudden onset of symptoms made it too difficult for her to even attend. Likewise, fatigue and muscle cramps caused her to postpone doing homework, forcing her to work a whole weekend to catch up. Taking some online classes was a strategy she was using to mitigate the problem.

The disabilities most often described were problems with mobility and dexterity, with some mention of cognitive disability in the form of memory loss. Difficulty with walking and balancing was commonly described. A few bloggers stated that they used motorized scooters at least part of the time, which allowed them much greater freedom to do things such as attend a concert and participate in an MS walk or other activism. Fatigue was generally a source of frustration, yet several bloggers took a philosophical view, and wrote of learning to listen to, respect, and care for their body. Several reflected on how the disease "forced" them to slow down.

A loss in dexterity was also a challenge. One blogger who wrote about creativity and art as a therapeutic process and commonly featured her paintings on her blog, wrote how losing dexterity has affected her art and lessons she was learning from it:

My right hand is now too weak to hold a brush. My left hand shakes. There could be no precise curved lines, no calm refined surfaces. I had expected the *resulting image* to teach me more about surrender. Instead, the *process* was my teacher. It seemed that each movement of hand and brush made expanding circles of anger, sadness, renewed determination and surrender. [emphasis in the original]

Interestingly, while I speculated that problems with dexterity might affect their ability to blog, only one blogger wrote about it as a problem. The topic came up in discussion and a

few said that they have difficulty typing but had various strategies of dealing with it. One said that she used to blog on her phone, but that had become more difficult because the keyboard was too small, another used voice recognition software, and another used a desktop computer because it was easier, even though she preferred using a laptop. Being able to type seemed like a less significant challenge than other physical difficulties. Although, it's possible that if someone has difficulty typing, that may be a factor in the choice not to blog. Finally, many bloggers referenced their difficulty in remembering everyday things. Bloggers were often humorous about it, but one wrote about it with frustration and sadness because it was affecting her relationships:

Today, I am discouraged and depressed about my friendship abilities. I don't know if I am a total idiot when it comes to communicating or what it is.

It's hard to go from hearing "you're a great counselor" and "you're so easy to talk to" and "you get it" to realizing that what comes out of my mouth is miles away from what is going on in my brain, and it's hurtful instead. And I can't even figure it out cause I've already forgotten what we were talking about, so I can't go back to defend it or explain it.

Emotions While a few bloggers wrote about difficult emotions such as fear, depression, loss, and contemplation of suicide, emotion was more integrated throughout the blogs. Emotion was conveyed implicitly, through humor, or on context of the subject (such as, joy from spending time with a grandson; frustration with a medical encounter; feeling accomplished by being able to be mobile in a scooter; having fun; satisfaction from connecting with others who have MS; etc.). The ways that emotions are described in the blogs will be discussed further in Chapters 5 and 6.

Interpersonal relationships

Relationships with family and friends were often constructed around the dichotomy between connection and disconnection. The most salient topic was the importance of family and friends and whether or not the blogger felt supported by them and involved in their lives. The support of family and friends, which helped bloggers feel good about their lives despite the illness, was contrasted by three bloggers who experienced family and friends cutting off communication with them after their diagnosis. That this abandonment caused a lot of pain was clear. Disconnection was associated with loss of or changes in relationships as a result of the onset of illness. Many of them wrote about the “invisibility” and unpredictability of their symptoms, which they felt made it more difficult for others to understand the nature of the disease, such as the fact that fatigue often prevented them from going out to social events. Bloggers wrote that sometimes others dismissed their disease as less significant than a terminal illness like cancer, and therefore were less understanding of them. In many cases this disconnection led to family and friends fading out of their lives. As one blogger wrote, “Eventually people have to go on with their lives. The problem is that includes spouses, children, parents, and siblings.” As this quotation demonstrates, the effect of MS on their relationships, was often written as, or suggestive of, a “before and after” narrative. This made it clear that the onset or development of the disease was frequently a major shift in bloggers’ social relationships.

Blogging is a way to regain agency

In the survey (Phase 2) I asked, “How would you feel if you couldn’t blog?” One participant responded, “I would be frustrated. I have always been a do-er. This way I'm still a do-er and maybe can help people in a different way than when I was working.” Other participants used descriptives like “crabby,” “isolated,” “alone,”

“silenced,” “angry,” and losing a creative outlet, which illustrated the importance of blogging as an emotional outlet and a way to connect to others.

As the quotation above indicates, blogging was something they were able to do despite other limitations. Fatigue and being less able to be physically and socially active was a theme that came up again and again in all three phases of data collection. Many of the bloggers described the changes and modifications they had to make on a daily basis to accommodate the significant fatigue they frequently felt. They often found these limitations frustrating, but some also wrote about learning to respect their bodies’ physical limitations, be flexible about what they expect from themselves, accept that they are not always able to do the things they once did with greater ease, appreciate that having MS required them to “slow down” their life, enjoy the friends and contacts they have made with others who have MS, become activists, help other, and nurture a love and talent for writing.

Awareness of and orientation to audience

I frame this section around the following questions: Who is the audience? Why write to an audience? What do bloggers want people to get from their blogs? What do they want or not want from their audience?

In the survey, respondents identified two primary audiences: each other, meaning other people with MS, including other bloggers; and family and friends. One is a primarily online audience, the other primarily offline. When asked “who do you think reads your

blog?” The top three answers, by a wide margin, were people with MS (n=16); other MS bloggers (n=16); and family and friends (n=14).

The question of why they blog has been addressed above but here it is useful to offer another angle by analyzing the results of the survey question “what do you hope readers get from reading your blog?” Answers can be grouped into three areas: inspiring self and others; relating to others; and being understood.

Inspiring self and others. Six bloggers described writing to give “inspiration;” “to keep going on with life;” that having MS “isn’t the worst thing in the world” and “only changes what I’m able to do but not who I am;” to demonstrate a “way of coping;” and to show that “even with the disease I have an active and full life. I also believe that they can see that in general having a positive attitude helps with the disease.”

The nature of this inspiration is to be positive *in spite of* illness with what appears to be a two-part goal: to inspire the blogger herself to cope with MS and inspire others. The presence of audience is necessary since it is through trying to inspire others that they are able to inspire themselves. Blogging gives them a way and a reason to inspire others and remain positive. It also challenges ‘healthist’ assumptions (which are both externalized and internalized) that to have a serious chronic illness is an inherently negative experience, that the chronically ill person is robbed of a full life, and relinquishes control of her body as a result of the illness. The choice to frame coping in a positive light is a strategy for authoring their lived experience. However, I argue that bloggers write within a cultural

meta-narrative that privileges positivity and discourages focusing on more negative aspects of life with disease. I discuss this extensively in Chapter 5.

Relating to others The common thread of connection and disconnection to others that runs through this analysis is further supported in what bloggers hope their audience gets. Five bloggers described wanting to relate to other people with MS; to provide “support and compassion.” Five bloggers’ answers indicated that, in relating to others with MS, they hoped to combat the feelings of disconnection and isolation they sometimes felt. As one wrote, “we often feel alone with this disease even when we are in a room full of people.” Another answered “while our disease may manifest differently our experiences and emotions are very similar.”

Two bloggers claimed feeling some ambivalence to an audience. Interestingly, one respondent spoke to her ambivalence about the topic of inspiration when she wrote “I don't really care. I've been told that it's inspirational because I *don't* focus on MS” (emphasis mine). The other describes how her experience with her blog changed from just her voice to influencing others and discovering a community:

I didn't initially care what others might gain from my blog. I was writing for myself, and mostly I still do. In the past several months though, I have learned that I am having an impact on others that I didn't realize was occurring. I receive so much positive feedback! In addition, I find support and a sense of community from those who are regular readers/commenters. Many of us have maintained contact outside of the blog via text messaging and emails. We check on each other often.

Being understood Six bloggers wrote of wanting to be understood by others in two ways: they wanted MS as a disease to be understood, and they wanted their lived experience to be understood. Understanding MS as a disease included being educated on

the medical aspects, such as its etiology (causation), its basic biological functions, and its expression (symptoms and progression). In wanting to relate their lived experience, bloggers wanted readers to understand what it is “like” to have the disease, including the negative effects on family and friends. One survey answer sums up the multiple goals she has for being understood:

A better appreciation of what it's like to have MS or other disabilities. An awareness of the importance of society's acceptance and support for those with MS and other disabilities. Knowledge of diseases causing disabilities and what people can do. How the costs to them and their family economically and emotionally are difficult. And for those with MS or a disability a sense that they are not alone.

Using words such as “appreciation,” “acceptance and support,” “knowledge and what people can do” suggests that this blogger wants being understood to result in some sort of action by others. We can infer from this answer that she feels these kinds of support are lacking.

Having established an overview of the blogs, a general profile of the bloggers, and some of their perspectives on blogging, I discuss two major thematic areas that emerged from my study and consider them within the larger theoretical frameworks I laid out earlier in this work. In the next chapter, I discuss the ways in which bloggers narrate their experiences online and analyze how their voice is socially mediated and negotiated. In the following chapter, I demonstrate how blogging is a practice of contemporary patient-hood and how, both by blogging and through, my participants are engaging in digital biological citizenship.

CHAPTER 5: NEGOTIATING VOICE

"I have never considered my blog as an MS blog per se. It's a journal of me. And since MS has become a part of me, well, it was only natural to write about it and the drama that is caused by the beast." –'sherri'

Finding voice

Bloggers negotiate their online voices within a political, social, and culturally-constructed framework that influences how they present themselves publicly via their blogs. This framework includes a constellation of scripts oriented towards presenting a positive attitude about coping with serious illness. Bloggers employ multiple overlapping scripts in navigating within the framework, which I outline as 1) having a positive attitude in coping; 2) enacting resistance; and 3) "venting." Silences, that is what is *not* written, are also part of the constellation of scripts that make up the framework. I argue that despite concerns that many users of social media do not consider the potential consequences of publicly sharing personal information (Agger 2012), the bloggers in this study have carefully considered and constructed how they present themselves. Overall, I argue that through the act of blogging, my participants create a mediated space in which to enact these negotiated practices and author life narratives.

Summary of findings

Enacting voice begins with the decision to blog. When asked in the survey why they chose to blog, participants described several interrelated motivations for making their personal narratives public: a love of writing, an emotional outlet, creating a record of their

experience, sharing information, finding and connecting to others with MS, and inspiring others. Writing was a passion for many of them and they identified both as writers and as bloggers. They identified blogging as a public vehicle for their writing. Several described their blogs as online journals or diaries, and some said they moved their journal writing from offline to online.

Blogging also helped them build confidence as writers. A few of them used their blogs to promote other writing, such as a memoir or book, or showcase their writing with the hope of getting more exposure or to get paid writing work. Writing was both an emotional outlet--a way to express emotions, clear their minds, etc.-- as well as a tool for organizing thoughts. This was reflected in the survey, where the greatest motivation for blogging was “coping with MS” and the second was “how I am feeling emotionally.”²⁶ It was also a way to reach out and connect to other people, particularly those with MS. One survey respondent summarized all of these functions when she wrote “I enjoy the therapeutic experience of writing in an interactive environment that allows me to connect with others who have MS around the world. What’s better than that??” Others expressed similar thoughts. ‘katewj,’ a participant in the Phase 3 discussion wrote, “one of the main reasons I blog is to maintain my mental health. Writing helps me understand what I am thinking and feeling and moves me to a more resourceful place.” Bloggers sometimes used it as a mechanism to help organize their thoughts, remember things, or, as discussion participant ‘sherri’ presented it, something to keep her “marbles all polished and shiny,” a reminder

²⁶ Survey participants were asked to choose the three most important motivations for blogging from a list of twenty-one reasons. Slightly more than half (N=11) chose “coping with MS” as one of the motivations. This far outweighed other answers. The next highest rating was for “how I am feeling emotionally” which was chosen by 6 participants.

that keeping one's mind sharp despite limited mobility and/or cognitive problems was of very important.

Also, bloggers who had had to give up working due to disability (which was reported by more than half of survey respondents) wrote that they missed the intellectual stimulation of working or engaging with other people and found blogging to be a way to use their minds and process thoughts or as, one blogger stated it, “by writing and reading, I can work my brain and rest my body.” This is an example of how the digital and the biological simultaneously overlap and shape each other, demonstrating that their experience is neither purely digital nor purely biological.

Identifying as bloggers, not “MS bloggers”

When ‘sherri’ wrote “...my blog is about me... not MS. I live with MS so naturally, it’s going to be on my blog,” she made the distinction between being a “blogger with MS” and an “MS blogger.” Since I was interested in the “MS” part of their lives, I thought of my participants as “MS bloggers” and had used the term in my introductory communication with the bloggers, the name of the discussion forum, and the first set of questions I posted to prompt discussion in the third phase of the project. It quickly became clear that at least some of the participants found “MS Blogger” to be a label that was too limiting and that didn’t allow room for their full experience as women blogging about their lives and perspectives. I realized that in making the assumption that the blogs were *about MS*, I was guilty of what we often do as a culture, which is to think of people with illness as having

limited lives. In some significant ways, illness does impose certain limitations of their lives, but it does not diminish their experience.

Similarly, some didn't feel they were part of the "MS blogosphere" (a term I used in communications, and had seen used on some blogs) for the same reasons. Interestingly, it was assumed that there was an "MS blogosphere," but that they didn't necessarily fit in it.

As 'fukymango' wrote:

My blog isn't primarily an MS blog - or at least I don't think of it as one. I write about all sorts of topics to do with health, medicine, and disability...I don't really think of myself as part of the MS blogosphere, either. The other blogs I read aren't MS ones. My online MS contacts are from Twitter, or from [an] MS chatroom.

She rejects the confines of an "MS blogosphere" due to the broader content of her blog, her reading of other blogs that are not related to MS, and her participation with other people with MS in other social media networks. The simultaneous and more general use of multiple social media applications illustrate that MS is situated within a broader dialogue. Interestingly, however, bloggers who rejected the confines still made distinctions between MS-focused and non-MS focused social media. Also, as the content analysis described in the last chapter indicated, titles, headers, autobiographical descriptions, and other blog elements such as MS-related blog "awards" make it clear that having MS is an important part of their online identity in these blogs.

A parallel can be made to other journal-style blogs that are generally categorized by a dominant identity characteristic, such as motherhood. The phenomenon of so-called "mommy blogging" has garnered national media attention (Belkin 2011; Hochman 2005; Mendelsohn 2010), developed a major presence at blogging conferences like BlogHer, and

become an income-generating practice for some women via brand sponsorships and paid advertisements (Joshi 2011; Sweeney 2013; Walker 2010). A few bloggers have become widely-read and well known, such as the very popular website dooce.com. Like some of my participants, some “mommy bloggers” have rejected the title and find it too narrow (D’Arcy 2010) and Powell (2010) writes that these blogs have become a lightning rod for good mother/bad mother discourse. Labels such as “MS blogger” and “mommy blogger” call attention to how identities are narrowed or limited into categories, but this study demonstrates that the act of blogging about their lives re-expands the narrative and actively writes against these imposed limits.

Writing against stigma

Modern Western culture has constructed the “normalized” body as disciplined; free of illness, disease, or disability; and assumes a long life span. The image of health is youthful, active, physically fit and thin, and, generally, white or at least conforming to a beauty aesthetic standard constructed by white people (Gruys 2012; Patton 2006; Wolf 2002). These constructions are particularly salient for women, whose bodies are generally more scrutinized and compared to idealized standards of beauty, sexuality, and health. A healthy body is constructed as productive, and therefore more valued; and independent, and therefore self-sufficient. By contrast, an ill body is viewed as less productive, less valued, and more dependent. This nearly-impossible standard of perfect health (which, even if achieved, is temporary) is set as the norm against which we compare and construct the false binaries of wellness and illness, and which is reinforced by institutions such as the

health care industry, some public health institutions, and popular media and literature (Metzl & Kirkland 2010).

To more completely understand what constitutes a normalized healthy body, we need to conceptualize its constructed counterpart – the ill body. Health and illness are not binary, nor are they on a continuum, but simultaneous and interwoven. States of health and illness, types of illness, and disabilities are socially and culturally constructed (Brown 1995). These ideas are influenced by power structures such as corporations, government agencies, and medical institutions that differentiate by gender, age, class, race; as well as the physical appearance or non-appearance of illness; the apparent severity of illness; and the cultural scripts that are assigned to them. Power is also produced in making such categories as well as derived from them. And they are also internalized and socially reproduced in everyday interactions.

To further analyze the cultural framework in which bloggers are writing, I draw from literature on disability, particularly as it relates to stigmatization. Garland-Thomas (2001) describes disability as:

...a broad term within which cluster ideological categories as varied as sick, deformed, ugly, old, maimed, afflicted, abnormal...all of which devalue bodies that do not conform to cultural standards (p. 2).

As Ju Gosling (2008), a disability rights activist, blogs stigmatizing social constructions of disabled peoples' bodies consist of assumptions that are scripted onto bodies and which exclude the voices of disabled people themselves. She writes that disabled people are defined by their diagnosis and by their degree of difference from the healthy "norm;" their

bodies are given greater attention than their other life experiences; their lives are assumed to revolve around their impairments and their quality of life is believed to be negatively affected by them; it is assumed that their impairments, not society's barriers, are what disables them; and that medical practitioners and scientists, not disabled people themselves, are the experts on disability. In particular, women with disabilities have been further constricted by perceptions that they are “helpless, childlike, dependent, needy, victimized, and passive” (Fine & Asch 1988, p. 4). While not everyone with MS has physical disabilities or identifies herself as disabled, several participants in this study who used mobility aids such as wheelchairs and walkers referred to themselves as disabled. In general, whether or not physical disability significantly affects their lives, some chronic illnesses are *disabling* and their ill bodies are the subjects of these constructions.

The shifts in everyday living and in social relationships often contributed to feelings of isolation. Challenges with mobility and travel that make leaving the house difficult, not being able to work, and symptoms such as fatigue, can all limit social contact. Eleven (out of 20) survey participants reported that they were not currently working due to disability. They were more limited in how often and easily they could leave the house and frequently wrote about the planning and negotiations they had to employ in order to do so. In addition to the physical effects of the disease that sometimes limited their in-person social contact, bloggers wrote of feeling emotionally isolated from being among people who did not have MS and therefore could not empathize or relate to their experience. This was a primary reason for starting and maintaining their blogs -- not just social contact, but social contact with people who could truly understand the experience of having MS because they have it themselves. Bloggers spoke of feeling a part of a community of understanding, often

mentioning that people in their daily lives often could not relate to or understand what living with the disease was like, or, as one blogger wrote, “No one else has a clue.”

Several participants described MS as an “invisible” disease, meaning that it is not always physically obvious, particularly with symptoms like fatigue or cognitive problems. This made it even harder for people without MS to relate to. For example, one survey participant had this to say about how blogging helped her feel less alone:

Sharing with others who understand what I’m going through because so many people don’t get why one day I can do something and the next day I can’t. Most MS bloggers know what it’s like to be misunderstood...Knowing you are not alone in this fight means a great deal.

Bloggers made distinctions between social relationships that were supportive or not supportive. For them, being supportive meant things like helping with tasks the blogger couldn’t do herself or which she found more difficult to do, such as running errands or house cleaning. It also meant being more understanding and accommodating of her physical limitations. Relationships with people who were not supportive generally faded away. This was met with a mix of feelings and experiences. Illness helped distinguish who their “true” friends were from people who were not supportive, but some felt sadness for losing friends who “moved on.” A few of them shared painful stories of feeling abandoned by some family members and friends who cut off contact following their diagnosis, such as ‘sherri’s’ account:

The day I was diagnosed, I called [my friend]... because, you know, that's what best friends do. I have not heard from her since. She told my daughter that she doesn't know how to come to terms with my illness. That has never made sense to me but it is what it is. I can't force her to remain in my life.

Being on the internet also provided a conduit when in-person interactions were difficult or limited. Connecting to others on the internet was a strategy used to expand bloggers' geographical networks and work around physical limitations or barriers to forming connections to give and receive emotional support. Overwhelmingly, bloggers said that it was important for them to connect to others, including 'sherri,' but she also said that while connecting mitigates feelings of isolation, it could not *always* eliminate them:

MS has made me feel alone, more than I choose to be. I don't know that connecting on line or any other way makes that feeling go away. It is an outlet, it is a communication device, it is a support system. But it doesn't make me feel any less alone really. I'm no longer the self I thought I was and that is very hard to come to terms with.

'grace2wheel' echoed this perspective poetically when she wrote "MS has built an acrylic wall between me and even my most intimate relationships...Something about the mercurial invisibility of this disease makes it so difficult to relate to."

Writing for an audience

Writing for an audience influences how bloggers negotiate their online voice and present a public identity. While the bloggers in this study chose how to present their voices, they did so with an acute awareness of readers, both known and unknown, and an implicit understanding that they must negotiate and moderate their voice and tone in order to present themselves in a favorable light. Carefully crafting their public presentation may also help them avoid potentially alienating or causing discomfort to their audience, which might increase feelings of isolation. As discussed in Chapter 2, narrative is a mechanism that helps shape or reshape identity and make sense of life, in this case, with illness. By

specifically identifying themselves as women with MS, they make it clear that having the disease is a core part of their identity. However, many of them emphasized that having MS is not their primary identity, but one of a cluster of characteristics and descriptions, such as wife, mother, daughter, sister, religious beliefs, interests, etc. The following header that appeared (Fig. 5) at the top of one blog demonstrates this desire to be seen as having a multi-faceted and more holistic identity.

Fig. 5



While public and private have become interstitial through social media, blogging is clearly seen as a public performance. Bloggers compose their narratives and, in doing so, make decisions about what information to share and how they share it. Hookway (2008) argues that the social anonymity of being online enables bloggers to write more candidly and honestly, writing that a “tension between visibility and invisibility gives blogging a confessional quality, where a less polished and even uglier self can be verbalized” (p. 97). In both the survey and the discussion phase some bloggers in my study wrote that their lives were an “open book” and that there was little about their lives they wouldn’t share

publicly. Indeed, as previously noted, most of the bloggers chose not to write anonymously. This suggests that the openness of the Internet as a medium may be liberating for some bloggers but it does not support a concern that people share information indiscriminately on social media, as some have suggested (Agger 2012; Albanesius 2010; Masum, Newmark, & Tovey 2011).

However free they may appear to be with information, my data indicate that bloggers in this study still carefully construct their online presentations. In their study of blogging and online communities, Bullingham and Vasconcelos (2013) concur, writing that “participants were keen to re-create their offline self online, but engaged in editing facets of self” (p. 101). While all 40 bloggers in my initial sample shared intimate portraits of their everyday lives, they demonstrated a broad spectrum of concerns about protecting their identity or remaining semi-anonymous or anonymous.²⁷ In fact, in the recruitment phase of this project, it was only after I conducted the content analysis and attempted to contact bloggers for participation in the survey that I discovered that almost a quarter of the bloggers had not provided any way to contact them directly. Likewise, some of them only identified themselves with nicknames and avatars and did not post photographs of themselves. However, this did not mean that they shared less or more information about themselves or that their identity was unknown to family, friends, and others they knew. This unexpected discovery provided insight about the ways in which bloggers identify themselves publicly and suggested that anonymity is not a fixed concept, but that there are varying levels of anonymity.

²⁷ There is always the possibility that a blogger has created a fictional identity for herself, however there is little to suggest that this phenomenon is rampant in blogging about chronic illness and I have no reason to believe any of the bloggers in the study engaged in this practice.

Writing within a meta-narrative of positivity

The results of my study indicate that bloggers present their voice within a meta-narrative of positivity, which is an implicit political and socio-cultural construction that includes multiple scripts that are continuously and carefully negotiated. As outlined at the beginning of this chapter, I categorize these scripts, which are tools to negotiate, perform, and enact identity, as 1) having a positive attitude in coping; 2) resistance; and 3) “venting,” described in greater detail below. Conforming to the script of 'positive coping' allows bloggers to present themselves as effectively coping and managing their disease. The 'resistant' script allows bloggers to challenge the meta-narrative of positive coping; confront and challenge assumptions and expectations placed on people with chronic illness and disability; as well as critique the political realities of their daily lives. “Venting” enables bloggers to express negative feelings like anger and frustration but, because it is presented as a temporary *departure* from more positive language, it lessens the risk of alienating readers who might feel uncomfortable by the expression of negative feelings.

These scripts are generalities and not meant to be interpreted as having strict guidelines. Rather they are often blended and, when seen together, they collectively push the boundaries of illness as a taboo subject. This framework emerged from the data via the juxtaposition of bloggers' voices on their blog (Phase 1 content analysis) and through direct contact with me and with each other (Phases 2 & 3, the survey and online discussion). The separate phases of the study provided a more in depth perspective than I would have been able to achieve from any of the phases alone. The content analysis of posts was conducted

without bloggers' knowledge and before I had any contact with them and therefore was not in any way directly influenced by my research. This allowed me to read how they presented themselves and what they wrote about. Asking them directly via the survey and the discussion, and bringing them in conversation with each other shed light on how they considered their writing. This cross-reading allowed me to see that there was much more going on than categorical or binary scripts, and that their voices were negotiated, overlapping, and nuanced.

I expected to find certain scripts aligning with "positive" or "negative" narrative and read those as mutually shaped by both individuals, and political and socio-cultural meta-narratives (Ehrenreich 2001, 2009; Sandaunet 2008). I assumed (correctly) that the positivity script was the default, that is, what bloggers felt they "should" be writing, but also which they chose to write, as was often the case. What emerged, however, particularly from discussion with bloggers, were contradictions and negotiations in crafting voice in relation to positivity. In analyzing the overall results of the study I was able to see that "negative" scripts were really scripts that resisted the meta-narrative of positivity and/or resisted hegemonic structures such as the medical establishment. Other aspects of this 'resistance' script emerged, including a desire to show the "dark side" of MS, which some bloggers felt was more truthful, and directly challenging social conceptions of the ill and disabled.

Finally, the script of "venting" emerged as something that was distinctive and neither categorically positive nor resistant. However, it borrows from both of them and presented a strategy for being able to navigate between two sometimes-incompatible scripts. In the following section, I provide examples of the critical ways that these scripts play out and overlap.

Positive coping The script of having a positive attitude toward coping with life with MS is organized around the assumption that having a serious chronic illness is a negative life situation that one would not choose for herself. In other words, it would be preferable not to have the illness but since she does, and there's nothing she can do to eliminate it, she makes the best of it. As 'funkymango' wrote in the discussion:

I don't "fight" MS...Waste of precious energy, in my opinion. It's there, and I can't get rid of it. Just got to accept it, roll with the punches, take what you can from it, and get on with living life to the full.

The use of this script was demonstrated throughout the three phases of data collection in a number of ways: using humor to make light of difficulties; using a narrative of inspiration; framing the illness as teaching the blogger life lessons; and writing about living a full life "despite" having MS. For example, one common slogan I found on the blogs was "I have MS, but MS doesn't have me." This script was produced both from a blogger's desire to focus on the positive for her own and others' benefit, as well as conform to a social expectation-- the two were interrelated.

This positive rhetoric is partly understood as a product of political and socio-cultural framing of illness and disability, and societal expectations. As Ehrenreich (2009) writes, this rhetoric, which she terms "bright-sided," is particularly true in the United States. These implicit expectations may also be internalized and reproduced by the ill person herself, a mechanism that Rose might argue we use to discipline ourselves (1998). A participant in Charmaz's (1991) study of people with chronic illness describes how she felt the need to perform the socially-sanctioned role of the ill person. In her explanation below, she refers to herself and others with disabling chronic illness as "cripples." In using this

terminology in this way, she employs a resistant practice of re-appropriating stigmatizing language to claim ownership over her experiences.²⁸ It also has the powerful effect of conveying how such language isolates people from the healthy “norm.”

...cripples must bear their lot meekly and cheerfully. A grumpy cripple isn't playing by the rules. And much of that pressure is self-generated. Early on, I vowed that if I had to have MS, by God I was going to do it well. This is a class act, ladies and gentlemen. No tears, no recriminations, no faintheartedness. (p. 201).

Following a similar line, ‘sherri’ interrogated the implied expectation that a blog about illness should not dwell “too much” on the negative when she posed the following questions to the discussion group:

how many of us are completely honest... in the raw, open up your eyes, life sucks sort of way? it seems like there are many out there who are blogging about chronic illness but sugar coating it in a sense....and by sugar coating it, does it help others?

i realize that it helps the author.... some have told me that by sugar coating it they can put a lighter spin on the situation and maybe in the process convince themselves that things aren't quite so bad...

i can understand that...

but... sugar coating... does that help promote the cause? does it help awareness of MS and what it does?

‘sherri’ suggests that putting a positive spin on her narrative may not be the most honest portrayal of her experience. The term “sugar-coating” implies inauthenticity and she questions whether or not this detracts from challenging the dominant rhetoric and educating people about the disease.

²⁸ This practice has been adopted by many social movements and stigmatized groups, including feminists (terms like ‘bitch’) and racial minorities (terms like ‘nigger’). The term “crip” (short for cripple) was used in the title of one of the blogs in my sample: “The Gimp Chronicles: Shade-Stealing Crips.”

Her questions provoked several impassioned responses that demonstrated that bloggers were very much aware of these implicit expectations and that they weighed these questions when deciding what tone and language to use in their narratives. Their answers also revealed the strategies and negotiations they undertook. For example, 'funktymango,' 'marie,' and 'katewj' all acknowledged that a more complete or "honest" portrayal of life with MS would probably be more negative than they generally portrayed on their blogs. 'funktymango' wrote that she is honest, but balances the more negative portrayal with humor because it helps "lighten the mood when I'm talking about what can be very serious - and scary - topics." She also chose to consider what she had gained from the experience:

The wonderful friends I've made, who I would never have known existed without MS. The way I'm learning to slow down and take each day as it comes - too much stress otherwise! The experience of studying for a PhD:²⁹ without MS forcing me to give up work, I don't think I would ever have had the courage. And now, my (very slowly) burgeoning writing career, which started with people reading my blog.

'katewj's' blog is specifically focused on her artwork and her creative process. She connects this to her embodied experience with chronic illness by writing about the physical challenges she faces in making art, such as problems with dexterity that affects her ability to draw. Perhaps because of this specific orientation, she chooses not to include a certain portrayal within the parameters of her blog:

Sherri, about "completely honest"...I think I'm always honest in my blog, but I certainly don't say everything about everything...If I need to "vent" I journal about it privately, but don't publish the results. I don't think blog posts have to offer solutions, but I don't just want to spew.

²⁹ Unfortunately, she was unable to complete the degree because of her illness and left graduate school.

If my goal were to give a complete picture of what it's like to live with MS, I guess my writing would be darker – a more complete truth. I don't know who that would serve, though. I get a feeling of "I'm not alone" reading other people's writing even without the gory details. I'm afraid adding more details would depress me. There is therapeutic value to a certain level of denial.

On the other hand, 'marie' agrees with 'sherri's' suggestion that a portrayal of the challenges and negative aspects of MS is generally more accurate and, for her, the benefits of writing about it "honestly" are worth the risk of focusing on the negative:

I have never tried to minimize how absolutely horrible it is to have MS, just the opposite, I have really made an effort to raise awareness of how devastating it is...That is part of the reason I started my MS Renegade blog. I had a hard time with some blogs that said they were "grateful" for MS or were relentlessly cheerful. I know attitude is important and that to be too negative can be like a self-fulfilling prophecy. But I felt it was important to be realistic.

These examples illustrate that bloggers are very much aware of the meta-narrative and that they make conscientious decisions of where to place their narratives in relation to it. They also demonstrate that while the meta-narrative may derive from social expectations and may be reproduced by the blogger, she may focus on the positive because she derives benefits from it herself. This was consistently found in all three phases: in the content analysis, a number of bloggers portrayed their blogs as inspirational, and bloggers in both the survey and discussion said that they hoped to inspire others to cope and in doing so, inspire themselves. It is clear that while bloggers may be reproducing a meta-narrative, they are deriving at least some psychological benefit from doing so.

Resistance An overarching argument of my analysis is that the very act of giving voice to their personal experience with illness, sharing information, and forming connections with others through blogging is enacting some form resistance against

hegemonic political, social, and cultural structures. These structures place people with illness and disability, particularly women, in a disadvantaged position. Portraying their lived experience, addressing some of the challenges they face, and describing how they navigate their everyday lives directly confronts stereotypical assumptions that the lives of people with illness and disability are incomplete or somehow lessened.

In this section, I focus on narratives of resistance that I found in the data. The first was in challenging the social expectation to portray a positive attitude in the face of serious illness, even if it is not the blogger's experience (in general or at any given time). Rather than aiming to be inspirational, some bloggers specifically chose to describe the difficulties of having MS without, as 'sherri' described, "sugar-coating" them, which they felt was a more truthful portrayal. Bloggers that enact resistance to the positivity narrative often identify themselves as being exceptional, making it clear that they are aware of the implicit meta-narrative but choose to challenge it. Similarly, some described choosing not to read blogs that were "relentlessly cheerful," as 'marie' described.

Interestingly, 'marie' maintained two separate blogs about her life with MS, which had very different orientations.³⁰ She identifies one blog as focusing more on bringing a sense of humor to her outlook on life. She identifies her other blog as focusing on the negative impact of MS on her life and the lives of people with MS in general in order to give a more realistic portrayal of the disease. For her, making the distinction between

³⁰ Only one of her blogs was included in my sample because I didn't want her voice to be over-represented in comparison to others. For confidentiality reasons, I cannot specify which one because I told bloggers I would not explicitly link their names or usernames to their individual blogs.

approaches to writing about disease and writing in two separate online spaces is a way for her to negotiate both narratives.

The second narrative of resistance that emerged was about advocacy. The voices here focused on critiquing policy and/or engaging in political activism, such as bringing awareness to the lack of handicap-accessible structures (like ramps) in public spaces, advocating for better health insurance coverage, or commenting on relevant current events. For example, one blogger responded to a speech by American presidential candidate Mitt Romney, in which he claimed that the “safety net” that is available for the poor offered sufficient financial support. In her post, she described what it’s like for her to be poor now that she is unable to work due to her illness, and the very difficult time she has had accessing the programs he talked about. The theme of having to navigate the bureaucracy of government assistance programs and health insurance came up several times on the blogs and in discussion. Those who wrote about it almost always commented on the irony that the time-consuming and frustrating burden of accessing services fell to the people who had limited energy to do the work. I will discuss this contradiction, as well as inequalities that further constrain some people in accessing quality care and resources, in the next chapter.

Venting The third script was about “venting,” which entailed discussing the difficulties of the disease, particularly physical difficulties, as well as how they made the blogger feel and how it affected their relationships with other people. This script emerged from the data and is significant because, while it departs from the positivity script, it is different from negativity or complaining. Its primary purpose is summarized by discussion participant ‘sheltiemom,’ who wrote “I started my blog really to vent. It helps me to write

and get the feelings out vs keeping them pent up inside.” Venting was sometimes positioned as a temporary departure from the script of positivity. Although bloggers sometimes described their venting as negative or complaining, they qualified the posts as being different from the blog’s usual, more positive or reflective tone. These posts were framed as a temporary departure and did not signal a fundamental change in the blog’s orientation. More often, however, venting was presented as describing everyday difficulties or specific stressful events in a tone or even direct questions that invited readers to relate to their experiences. One blogger recounted a phone conversation she had in which she portrayed herself as feeling better than she did. The need to negotiate what is a common, but loaded question for some people with serious illness was frustrating to her and she asked her readers, “Does anyone else try to present themselves differently? Do you feel better or worse for it?” In this case, five people commented, relating their own similar experiences and thoughts on how to handle it.³¹ Along with describing their experience, bloggers frequently reflected on the effect MS has had on their lives, again often writing directly to others with MS. As one blogger wrote “We all know it absolutely sucks to have MS.” They also compare life with MS to life without it, often in terms of their lives ‘before’ and ‘after’ their diagnosis and the onset of the disease, or wishing for a return to a previously healthy self. After describing an outing to a concert at which she got a seat up front because of being in a wheelchair, one blogger wrote:

Sometimes this wheelchair has its advantages. I actually got a perk because of my MS. But to be honest, I wouldn’t think twice about trading the wheelchair in for some working fabulous legs and a brain to match!

³¹ As I stated in chapter 3, I did not systematically analyze comments because they are not a reliable indicator of who is reading, or even who is commenting, since bloggers can remove comments. However, I did read them and some observations such as this one are useful.

While most blogs had an overall tone of positive coping and/or venting, scripts varied within each blog and sometimes within each post. Narrative mechanisms such as humor and reflection were used across the framework. Humor allowed bloggers to lighten negative descriptions, express sarcasm, and invited readers to relate to their experience. For example, this blogger wrote about how her reactions to the symptoms of MS have changed over time:

Before I left my childbearing years (that time frame where I strangely "forgot" to bear *child*), there seemed to be a monthly pattern of exacerbating aches and pains...of fatigue...of worsening Multiple Sclerosis symptoms...of **FOUL MOOD**. :-) It would pass, generally like a finely tuned atomic clock and usually with anatomical precision...shortly after dear friend "Flo" began her monthly visitations.

Engaging in reflection also helped them make sense of illness in their lives and locate larger meanings or lessons from the illness, such as focusing on benefits of making new friends and being forced to "slow down" and appreciate life more than they did before they became ill. For several of the discussion participants, striking a balance between tones was seen as a way to realistically portray MS without being "too negative."

Silences

In addition to the written or voiced scripts, I explored the idea that Stuedahl (2010) puts forth of listening for silences. That is, what is *not* written. Stuedahl argues that paying attention to the spaces between speech -- or the silences -- can reveal information that may be overlooked in focusing only on the written or spoken narrative. Citing Foucault (1978)

she writes, “silence is an element that functions alongside with what is said and should be understood as part of existing overall strategies” (p. 169). Silence is not absence but is “a present and active part of social practice – a product of intention and agency” (p. 169). Looking for silences should also incorporate reasons for being silent, or being kept silent, such as the scripts that bloggers use in negotiating their writing about the difficult and sometimes taboo subject of illness.

Online communication requires a different kind of “listening” than in-person interactions. In this study, silences can be looked for in the narrative text of the blogs. When asked about their blogging practices, bloggers (both in the survey and in the online discussion with other bloggers) shared that there are some subjects, such as certain physical symptoms, mental illness, relationships, and sexuality, which they chose not to write about at all. An acute awareness of an audience, especially one that was known to them (generally family and friends) influenced some bloggers to negotiate their voice with this specific audience in mind, sometimes “censoring” themselves. These comments suggested that even in the open and potentially empowering medium of blogging, these narrative scripts are weighed.

Silences can also be located within the online discussion itself. While the mode of analysis was text-based and took place across an interrupted time sequence, paying attention to silences in the context of an online participatory discussion forum revealed patterns that participants engaged in to maintain parameters for talking about life with illness. While the five most active participants were very open about their personal experiences and perspectives, the less active participants were either less open and/or communicated less. In this context, there are many factors that could have contributed to

their lower rate of participation or sharing, including a lack of time or a lack of desire to participate more frequently, but it is worth conjecturing that they may sometimes have remained quiet because of a lack of comfort with the subject material or sharing some information with the others. Silence could also be seen between the bloggers through subjects they chose not to take up or particular posts they did not respond to. This is suggested by one blogger who responded to my question “Are there things...you don’t blog about?” She wrote, “I almost skipped this questions...but...this is probably the one place to say it.” She went on to write about “how much appeal ending my life has.” She made it clear that she was not actively contemplating suicide, but the emotional, physical, and financial costs of her illness were a very heavy burden. She wrote, “just once, I wish I dared write about it on my blog. I just don’t think my readers are ready to hear this type of grim reality without panicked over reaction.”³² The bloggers who responded to her were supportive and empathetic and a few of them acknowledged that this was a topic they, too, had thought about, so they could understand her feelings without being overly concerned that she might actually take her own life, as people who read her blog might.

‘sherri’s’ suggestion that she and other bloggers may “sugar-coat” the way in which they portray their experiences on their blogs, and the ensuing discussion, highlighted a particular kind of silence. The question generated strong responses that made it clear that

³² While I was very pleased with how the discussion went overall, I have one very big regret. Because I was both afraid of participants’ losing interest in the discussion and eager to conclude my data collection, I announced the impending conclusion to the discussion almost immediately after this participant posted about this very sensitive subject. As a result, the focus of the conversation shifted to wrapping up, sharing contact information, and answering a few remaining questions. I quickly felt I had made a mistake shifting the conversation so abruptly. By not listening to her fully, I did not honor her story or the trust she had placed in me by participating in the group. It was a regrettable reminder of how sensitive researchers need to be toward their participants.

bloggers carefully consider what they write about on the blogs and how they write about it. In discussing what they wrote about, whether it was deliberately avoiding certain topics related to illness, using humor to frame difficult subjects, qualifying or justifying their choice to write about “negative” subjects (i.e. “venting”), or purposefully challenging the implicit expectations of people with illness to maintain a positive attitude in their public communication, it was clear that bloggers understood a common meta-narrative and made conscious decisions about where to place their writings within it. Their reasons for choosing to remain silent are influenced by being kept silent by a meta-narrative that could potentially highlight their sense of isolation if it is disrupted and causes discomfort to their readers. The implicit understanding of and adherence to the meta-narrative of positive thinking is heavily influenced by a preconception that “too much” negativity can make their audience, particularly those without MS, uncomfortable and alienated. If the meta-narrative of positivity is not maintained, readers might choose to not to read the blog again and the blogger will not be “heard.” There may be other motivations to remain silent, including concern for family and friends who read their blog and may worry about them. Likewise, they may not want to feel the discomfort and concern themselves.

Occasionally, bloggers gave voice to these ‘silences’ such as this blogger who wrote about a scenario she often encounters when people ask her how she is feeling:

I had to make a choice: do I make her feel better with some sappy response, or do I just say, “Well, you asked.” This time I chose door number one, and I said that I really was fine with it all (lie), I found so many things to occupy my time (bigger lie), and things could always be worse (Pinocchio’s nose is really growing!) I think I do this so people won’t see me as a complainer; instead, they’ll think of me as being so brave in the face of a crippling menace.

The irony of publicly reflecting on something she won't discuss privately supports Hookway's (2008) finding that the relative anonymity of blogging may provide a space in which bloggers feel more comfortable dealing with painful subjects, which they want to give voice to but which may be more difficult to negotiate in person. The blogger quoted above concluded her post by posing the question "does anyone else try to present themselves differently? Do you feel better or worse for it?" This question was obviously targeted towards other bloggers with chronic illness, suggesting that in some cases, bloggers specifically address their writing to a certain type of reader. Likewise the post may have the benefit of indirectly communicating to readers the blogger might encounter in person how the blogger might feel in similar situations. Although most of my participants did not blog anonymously, they revealed limited personal details, such as only their first names, suggesting that they wanted to maintain some level of privacy. Also, I argue that the relative anonymity of the audience influences the greater freedom a blogger might feel to write about difficult subjects. The bloggers in this study did not fully know who their audience was but they seemed to assume that other people with MS read their blogs, and that their audience as a whole was, in general, sympathetic. As a result, they may feel a certain trust in their audience to be understanding, yet they do not have to confront anyone who they may be uncomfortable engaging with directly, or be concerned about making someone else uncomfortable.

While locating and interpreting silences in an online discussion is a subjective exercise, it is important to consider them. Likewise, it is important to leave room for the silences of bloggers who chose not to answer the survey at all or take part in the discussion,

and, more broadly, the unknown number of women with MS who do not choose to author a public online voice.

Summary

While a socio-culturally produced meta-narrative of positivity may place some constraints on writing about life with illness, simply writing about it publicly complicates and helps to reshape the paradigm. And while social constructions of illness and disability can be reproduced through narrative, they can also help to normalize stigmatized experience. In giving voice to their experiences and negotiating their voices through the mediated space of blogging, they ultimately alter the dominant rhetoric. It seems most appropriate to conclude with the words of blogger 'grace2wheel' who described learning to distinguish her voice among many others in her life. Here she illustrates the sometimes strange and ambiguous relationship between the virtual and the physical:

One of the things I am the most surprised by and struggle with is when my readers comment on and carry my posts over into my 'real' life. I prefer to keep my blog world more like a private, but public, journal. And, if one of my readers also knows me in the real world it is odd when they bring up blog topics for discussion...or when a family member or friend argues with my experience. "Why didn't you tell me about that," or "I didn't know this or that about you." Another area that is a challenge is the divergent opinions on what the focus/theme of my blog should be...for a while I felt rather stuck trying to make everyone one happy until *I finally realized that this is my voice, my blog and I can write it however I choose.* (emphasis added)

Her words articulate the unique standpoint of the blogger: she is purposefully writing to a public audience yet may feel discomfort when online and offline come into conflict.

CHAPTER 6: PRACTICING PATIENT-HOOD

"I like being an informed patient but it does make for a lot more work. I guess I kinda feel that it is just part of being a patient. You need to be able to understand what is going on so you can advocate for your care." – 'turtlespeed,' discussion participant

Locating the practice of patient-hood

In this chapter, I argue that contemporary patient-hood is practiced at the conceptual intersection of biological citizenship and participatory patient-hood. I use the term "contemporary" to describe the current social construction of patient-hood, which I described previously as having undergone significant shifts in the past few decades. While idealized rhetoric celebrates patient "empowerment" and suggests that a patient can now achieve equal partnership with her physician (provided she assumes individual responsibility for self-educating, etc.), it is more accurate to say that the role of the patient is no longer that of passivity and unquestioning compliance, but that she is both enabled to and expected to assume a more active role. Contrary to the rhetoric of partnership, however, the patriarchal model of medicine in which the unequal relationship between physician and patient is based on the commodity of "expertise" remains the standard. In conjunction with political pushback against physician dominance that prompted social change beginning in the 1960s, other pressures helped shape the conception of the ideal patient, namely a shift in how we view illness itself. For example, the conception that some illnesses may be "preventable," namely through the individual's behavior choices (as Knowles (1977), cited in Chapter 2, argued) reflects the neoliberal interests in encouraging the "enterprising self" (Rose 1998). Shifting both the responsibility and the consequences

to the individual relieves or offloads the state's responsibility to address factors such as social infrastructures and policies that support the public health.

Contemporary patient-hood is centered around body governance. A series of demands are placed on the body of the (ideal) contemporary patient, rooted in the neoliberal ethos that privileges individual responsibility but confines it within established power structures. First, she must govern her body to prevent or mitigate illness. In order to do this, she is expected to maintain certain bodily states that can affect health (namely through so-called "lifestyle" behaviors such as diet and exercise) regardless of environmental, socio-cultural or other factors and encounters judgment and blame for failing to maintain these bodily states. Second, once she becomes a patient, whether an illness is "preventable" or not, she is expected to perform a balance between responsible and participatory *and* compliant patient.

The differences between the conceptions of 'participatory patient-hood' and 'biological citizenship' are mostly rooted in conflicting orientations toward the rhetoric of greater patient engagement through individual enterprise. These conflicts are important in order to understand the argument I make that patient-hood is practiced as a negotiation between the two. The key difference in orientation is that participatory patient-hood is an idealized concept that envisions opportunities in revised roles of patients and medical providers, but which rests mostly on patients assuming greater responsibility. It assumes that a cultural wave carried by enthusiasm for new technologies will ultimately lead to advances in medical research and better health outcomes. Biological citizenship, by contrast, is built on a critique of this rhetoric and argues that the former masks neoliberal interests in shifting responsibility from the collective (state) to the individual. In this light,

participation is constructed as an imagined right, when, critics would argue, it is actually obligatory to performing the role of participatory patient. To paraphrase Rose's (1998) argument, the state does not need to govern our bodies, because we will do it ourselves. It is at the intersection of these two conceptions and the expectations required of both, that patient-hood is practiced in the everyday.

I argue that Rose's theoretical conceptions offer a much-needed critique of the construction and practice of participatory patient-hood. The influence of neoliberal policies on the everyday lives of patients needs to be questioned because they support the continued capitalization of the health care industry and reductions in support services, and in doing so, broaden inequalities and increase constraints on the individual. However, Rose does not directly apply his theory to empirical research. When applied, gaps in the theory are revealed, primarily that, in addition to the increasing burden, there are also real benefits to the ill person. While participation may be seen as obligatory, it can also be beneficial by giving patients greater agency and access to information and a role in making decisions about their care. My research demonstrates that contemporary patient-hood can include practices that are both empowering (participation) and disciplinary (biological citizenship), as well as those that resist either paradigm. It is this constellation of factors that I call "practicing patient-hood." In this chapter, I discuss the themes that arose from my research that demonstrate the ways that is enacted.

Blogging as digital biological citizenship

Rose and Novas (2002) claim that the collectivizing aspects of biological citizenship are increasingly significant in reproducing individual body governance. As previously described, they are interested in the ways people acquire, produce, and share specialized scientific and medical knowledge by laypeople ('informational bio-citizenship') and include health activism ('rights bio-citizenship') as well as new ways of making citizenship by linking communities electronically ('digital bio-citizenship'). These aspects of biological citizenship were enacted by the bloggers in this study, most notably the use of social media to further and re-shape this kind of citizenship. The rapid and widespread use of social media that has occurred since these theories were developed makes the significance of digital bio-citizenship even greater. I argue that these bloggers are biological citizens. They assume the role of the responsible patient – they educate themselves and others; share experiential knowledge; form collectives; and engage in advocacy and activism. More specifically, in enacting these practices through and within blogging, they reproduce and enact digital biological citizenship.

Blogging helps these women be participatory patients, however, one problematic aspect of this construction is that it fails to acknowledge that many of the structural inequalities endemic in health care are not erased by the democratization of health information. Numerous factors aside from comfort with using the Internet and access, and a desire to blog, affect a person's health and well-being, such as access to resources, and ability to manage their disease, variations in severity over time, disparities in socioeconomic status, race, gender, social support, and severity of illness. For example,

factors such as historical racism in health care contribute to a continued lack of trust of doctors by some black Americans. Disparities in social capital (education, social class, financial stability, etc.) and stable social supports may negatively affect a person's knowledge of and access to resources, information and care, and affect an ill person's ability to navigate the complexities of the health care system and receive the care they need.

The bloggers in my study come mostly from a fairly privileged group: almost all were white, highly educated, and had significant social support from family, friends, and medical providers. I did not ask about annual income, although I did ask about employment status. While more than half reported that they were not working due to disability and some were definitely struggling financially, overall, their social capital (Bourdieu 1986) placed them at an advantage in having the resources necessary to navigate the complex systems of health care and social services, locate information and educate themselves, communicate effectively (including contesting) with their doctors, and have greater agency in their lives.

Blogging about life with chronic illness is a practice of contemporary patient-hood. It is a practice in and of itself, as well as a forum to narrate how they engaged in other practices. Three overarching themes of practice emerged from the blogs: assuming a lay expert position; relationships with medical providers; and problematizing advocacy.

Lay expertise

The bloggers in my study occupied a unique niche, which I call the experiential lay expert, and often linked the medical knowledge they acquired with their personal experience. They wrote detailed posts describing symptoms they were experiencing and well as how they were dealing with them, reported on current treatments and their effectiveness, and discussed the strategies they employed in their daily lives to accommodate the illness. ‘turtlespeed,’ quoted at the beginning of the chapter, noted that performing this role was “part of being a patient” and it was clear that many bloggers, particularly the discussion participants, felt that it was included in their responsibilities of being a patient. As bloggers, many of them also assumed the role of educator. Blogs often contained basic factual information about the disease and/or linked to educational websites, such as the National Multiple Sclerosis Society. More significantly, many of them tracked developments in research; treatments including pharmaceutical, holistic, and alternative; and lifestyle factors such as diet and exercise; as well as broader developments in health care policy. In addition, they placed themselves in the role of “translator,” breaking down medical language or complex findings into more general layperson language.³³

³³ Significantly, ‘funkymango,’ the only participant from outside of the United States (living in England), offered a unique perspective because she lived in a country with a national health service. She described that people with long-term conditions are recognized to have expertise and knowledge about their own conditions, which is recognized and respected by doctors. They can both attend and teach “expert patient courses” on subjects such as pain and fatigue management and communicating with healthcare professionals. While the United States does not have this formal structure, a broad range of stakeholders in the health care industry (insurance companies, advocacy organizations, public health agencies, etc.) feature patients with “expertise” in educational and marketing efforts, particularly through social media.

Choosing to adopt the role of educator and translator meant assuming responsibility to readers to provide accurate and up-to-date information that was supported by scientific research or other evidence that was considered reliable. While they were careful to provide accurate information supported by sources, they usually made the disclaimer that the content they relayed was their own opinion or based on their experience, and was meant to be informational only and in no way taken as expert medical advice. 'Brass and Ivory,' who blogs frequently about current research and policy developments included this disclaimer in the static sidebar of her blog:

Medical information is current as of the date of publication. Any updates to information will be similarly dated. Nothing here should be taken as medical advice. Always consult with your physician when making personal medical decisions.

Using a more humorous approach, 'Brain Cheese' wrote in a relevant post:

Let me first put on my lab coat, stethoscope, and straighten my diploma on this virtual wall...the diploma I earned studying at the University of Internet, the esteemed College of Wikipedia...and the School of Hard Knocks. As I've said before, I only PLAY a doctor on the Internet! But, I AM one of the experts regarding my OWN body, so I will (and can only) speak to it. **DISCLAIMER:** YOUR body is an absolute mystery to me and any advice you seek should be obtained from a qualified medical professional who has earned a degree from an accredited school, NOT the Internet. (emphases in the original)

Concerns over providing accurate information were more thoroughly explored in the discussion. Bloggers shared with each other their feelings of responsibility to be reliable and provide accurate sources of information and felt that there was much at stake if a reader encountered dubious information.

'sheltiemom' noted the benefits and risks associated with using the Internet to get information when she wrote, "we do have to be careful because while the internet can be helpful there is alot of Crap info out there also. It seems everybody has some crazy cure for MS." In response, funky mango wrote "This is so true...I think this puts some responsibility on us as MS bloggers/bloggers about MS to make sure the information we give is accurate."

Similarly, 'sherri' warned:

There are bloggers out there who do their own "research" and draw their own conclusions, then go and post it as medical based knowledge. this is very dangerous. if a newly diagnosed or very naïve person reads the information as legitimate, they might face some problems.

Bloggers also distinguished between providing reliable factual information and making it explicit when information was based on their opinion or personal experience. For example, 'katewj' wrote "while I rarely write about the medical aspects of MS, when I do I am very careful to talk about my experience and not make sweeping statements." 'sherri' also made the distinction between the level of responsibility and the orientation of the blog:

...i think that being a personal blogger carries some responsibility but not near as much as someone who is blogging and calling it research...those research based bloggers should be held to a much higher level of responsibility and standard.

For 'sherri,' other bloggers' personal experiences were the most helpful to her because they supplemented the information she received from her doctor or researched

herself, as well as learned from others about daily life with the disease. She wrote that on some of these blogs

...there was no declaration of fact -- only personal stories. in my mind, these were the best sources of information for me. i could compare what i was reading on personal sites to research or things my neuro had said, which helped me understand the disease.

Ultimately, however, the responsibility lies with the readers, as 'sherri' writes "to be very cautious to do their own research and ask their own questions of the doctors."

Developing expertise about the biology of disease provides a context in which to place the embodied experience of the disease, but the most intimate knowledge of the disease comes from living with it. Bloggers' experiences were often framed by describing daily experience – descriptions of symptoms, notable incidents like a fall, making accommodations in daily life for fatigue, or pushing oneself too hard. Bloggers' embodied knowledge was acquired over time. As they gained experience, how they reacted to symptoms or relapses sometimes changed. For example, 'Brain Cheese' wrote on her blog:

I have learned the fine art of "wait and see" before frantic 911 dialing of my doctors. I have learned if it interferes with my functioning enough, I SHOULD seek advice/call my doctor. I have learned there are many "home remedies" and healthier choices I can make to assist in coping with MS, such as diet, exercise, social stimulation, rest, etc. And, I have educated myself by devouring information about MS...weighing out the pros and cons of my learning, and listening to my inner wisdom to tell me which pieces of this learning are important for me to incorporate into my own well-being. I have taken my neurologist...off speed dial and added speed dial numbers for massage, supportive friends, physical therapy, calling in sick for work when I need to rest, and an assortment of *other* urgent numbers that support my wellness. [emphases in the original]

Bloggers felt satisfied, or in some cases vindicated, when experts validated their embodied experience, especially when it had been met with initial resistance, such as a diagnosis that was initially underestimated or dismissed by doctors, or an unconventional treatment that turned out to be effective. 'Just My Thoughts' wrote a post in which she described taking a regimen of high doses of Vitamin D at the recommendation of her doctor a few years prior. She credited it for her having had fewer relapses since then. At the time, however, the treatment was unconventional and others had been skeptical about its effect. In this blog post she wrote that she had just seen media coverage that studies had shown it to be effective for prevention and treatment of MS, and provided several links to the information in her post. Beginning with her personal experience, she was able to validate it through scientific findings and her doctor's status as a leading researcher.

Enacting participatory patient-hood

In the discussion (Phase 3), I asked bloggers if they felt their doctors expected them to be an informed patient by performing the tasks of self-educating about MS, staying up to date on new developments in drugs, treatments, and medical research, and dealing with things like insurance companies and disability benefits, and, if so, if they found these expectations empowering or burdensome. The data revealed that both the necessity and opportunity to become a participatory patient was not necessarily seen in the same light. Most of the discussion participants saw it as simply part of being a patient and that it provided opportunities for patients to feel more in control of their life with illness. The

blogger of brassandivory.org described herself as “professional patient by chronic illness,” indicating that chronic illness required her to adopt this role.

This finding highlights the ambivalence some bloggers felt about what the disadvantages of heavy expectations of patients might be, as Rose’s theory implies, as well as whether or not they were filling a socially-expected role. For them, being informed and bringing that information to their care had direct effects on their experience with illness. About being an engaged patient, ‘funky mango’ wrote,

I’m all for it. I want to be a partner in my healthcare. It’s my body, so if it’s down to choosing between two meds (for instance) I want to be involved in the decision-making.

Similarly, ‘isbe’ wrote, “I want to be knowledgeable about my disease and the treatments for my disease. I think you need to do this to be proactive in your own health and to know if the doctor is saying something completely off the mark.”

Encounters with medical providers

Not surprisingly, medical providers played a significant role in bloggers’ lives, even when actual encounters are infrequent. This significance was not only important to the physical treatment of the disease, but to their emotional experience as well as portrayed online. Encounters and relationships with medical providers were most often described in polarized terms: either positive experiences or negative/contentious experiences. In other words, there were no ambivalent descriptions. When I questioned bloggers about their relationships and encounters with medical providers, I used the generic term “doctor.”

However, participants talked primarily about their interactions with neurologists and his or her staff, who are the specialists that oversee their MS treatment specifically. These important relationships were negotiated between what bloggers expected of themselves as patients and what they expected of their neurologists. The nine bloggers in the discussion very much wanted to be informed enough to be part of decision-making in their care and wanted doctors who considered and respected their knowledge. Being informed also enabled them to be able to question doctors' knowledge and disagree with them when necessary.

Overall, the bloggers in the third phase discussion viewed the idea of being knowledgeable about the disease and having an active role in decision making and treatments positively. They also viewed it as their responsibility *if* they wanted to feel equipped to engage with their doctor and make decisions. 'Sheltiemom' implied that ease of access to information via the Internet did place some responsibility on the patient when she wrote "I don't think our doctors expect us to be educated but most probably appreciate it if we are. In this world where info is easier to access on the Internet it is important for us all to be our own advocate and be informed." That is, to be uninformed was to not be able to advocate for oneself.

Bloggers' ability to fill the role of self-advocate and partner in their care, however, was contingent on doctors meeting patients' expectations. They expected doctors to respect them as people, treat them as knowledgeable patients, and to care about them. Ultimately, they still wanted their neurologist to be most knowledgeable and able to guide them in decision-making. So while patients wanted to be considered a partner in their care,

they also sought to maintain the imbalance of power that reproduces the paternalistic model of health care to a certain extent.

'ellie,' a former physical therapist, said that she was "treated [respectfully] as a person with knowledge" by doctors most of the time. She enacted the role of the engaged and responsible patient by maintaining a chart of her health, which she brought with her to visits however, she wrote, "even though I am and want to be a knowledgeable partner I need him to be a caring MD." She described her recent appointment, in which he was attentive and supportive, and wrote "he was my physician and I was his patient...and that's what I needed at that time." 'katewj' also described feeling the need to direct her own care: "my treatment is very much 'in silos' and I have to be the communicator who thinks to ask one specialist about the effects generated by another." She also wrote:

I want to be an empowered, informed patient AND I hope for doctors who are more informed than I. My favorite approach is the one my rehab doctor uses: 'What's bugging you most and what could we do about it?' Together we problem solve, using her medical expertise and experience and my experience of living with this body.

Several bloggers described the satisfaction they felt in being included in making decisions about their care, such as 'sherri' described, "he [her neurologist] gives me his opinion, allows me to research things, and then together we make decisions about what is going to be next."

Several described themselves as "lucky" to have good doctors, indicating that there is a common perception that there are many doctors who would *not* respect them, listen to them, or work with them as a partner. Most of the discussion participants described having had some negative experiences with neurologists at some point and, if they were able to,

had elected to find a new doctor who met their expectations. 'sheltiemom' described a neurologist who had a "go home sit on the couch and die' attitude." She was able to switch to a doctor who was more proactive and receptive to her participation. Three of the bloggers, however, had either not been able to switch to a new neurologist or had switched but still not found one they were happy with. 'grace2wheel' described "an endless battle with doctors who have too much power over my access to medical care as well as the all important disability insurance. To be blunt, I dread seeing my neurologist." 'marie' wrote that she been to three neurologists in her local area:

I have generally been disappointed in my encounters with providers. The neurologists have been mostly arrogant and close-minded, needing to be in control and, locally, out of date with treatment protocols. Very threatened by any suggestions of knowledge by me, the patient... It is very disheartening, as a patient with a chronic disease, to feel you are not understood or respected as an intelligent, informed adult.

While most assumed that the neurologists they had seen had expertise, a doctor who did not meet their expectations was one who assumed a more patriarchal and less personalized approach.

In the roles required of contemporary patient-hood, the rhetoric of body governance is reproduced. Patients are enabled to be "experts" of their own illness but the inherent power structure in medical care limits their role to contributing information to the doctor's expertise and sharing in the decision-making. The extent to which their knowledge, experience, and desire to help direct their care, however, is contingent on their medical providers' sharing this ethos. Patients are able to enact resistance by contesting doctors' opinions and expertise and choosing to change doctors, if this option is available to them.

Furthermore, blogging offers them opportunities to describe medical visits, their interactions with doctors, and how they reacted, placing them in a prominent position in the narrative.

Encounters with the National MS Society

The issue that most closely demonstrated the troubling conception of biological citizenship was bloggers' experiences with the National Multiple Sclerosis Society (NMSS), the largest MS advocacy organization in the United States. Early in the discussion, 'marie' posed a question about participants' opinions of the NMSS that sparked a lengthy and impassioned thread. I located some of the same themes on blogs in the content analysis, although I also found several posts promoting fundraising for the organization, primarily for the MS Walk, which is one of their most high-profile events.

Bloggers were frustrated by a number of things about their experiences with the NMSS. The primary complaint was that the organization marketed heavily to them to engage in fundraising, particularly through participation in the walk-a-thon. The irony of the organization asking them to put their efforts into fundraising given that many of them have physical limitations that impact their mobility and energy levels as well as their financial situation, angered some of the bloggers. As 'marie' wrote,

...in the past two days I have gotten four calls from telemarketers paid by the NMSS asking me to distribute literature for them about MS. This is a laugh in itself as I am practically housebound.

Others agreed, including 'sherri,' who wrote,

Personally I get pretty ticked off at the MS Society.... they expect that those of us WITH MS are going to be able to get out there and pound the pavement to collect monies. Much of the time, that just isn't possible. I get all sorts of phone calls, emails, and snail mail weekly at least.... all of these things are either asking ME for a donation, or asking me to get out there and beg for money...

Likewise, 'ellie' described an advocacy meeting she once attended in which "we were told we should get out and help them raise money! What they raised was anger and resentment."

Bloggers were also sometimes embarrassed by the idea of asking their friends, family, and community for money particularly in a bad economy when so many others were feeling financial hardship. Both 'sherri' and 'marie' suggested that the money they asked of family and friends would be better put to use helping them buy everyday supplies to help them with their illness. Some of them had also read the society's annual report and were dismayed that so much of the funding went to administrative costs. Furthermore, some of them had approached their local chapters asking for direct assistance, such as help in acquiring an assistive device and either received no response or a token response with no follow up. Based on participants' descriptions, some local chapters seemed to be limited to representing and administering the national organization's goals and activities.

'sherri' expressed her frustration, writing

I do not know of a single person who has any direct help from NMSS. Not one. And neither does my neuro. Yet people just keep walking, biking, swimming, and whatever else they do to raise money.

I'm not doing it anymore. I'm done.

The few times I've contacted them for assistance or information, I got no reply. I call and leave messages that don't get returned. I write letters and emails with no response.

I'm done. [formatting in the original]

Finally, they found the overall mission of the NMMS unclear.³⁴ While they acknowledged the importance of advocating for and funding research, they were clearly frustrated by the absence of direct help from an organization that is the most prominent public face of MS. Expressing dismay at the high salaries paid to senior staff at the NMMS while feeling that she received little support, 'sherri' called attention to the unpaid labor that patients perform:

It's disheartening to me that there are so many well-educated, highly motivated people sitting at home unable to go to a job when they could be doing work for NMSS or any other organization, from home on the internet... why not pay those people who suffer with the disease to do the research papers, blog posts, etc?

Her response, of course, highlights that being a blogger is enabled by social capital, and calls attention to how disability can diminish a person's "value" in the marketplace. The NMMS operates as a top-down organization, thus perpetuating hegemonic power structures and ignoring many opportunities to involve the people they are advocating for in meaningful ways.

³⁴ The society's mission statement is "the Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward."

That participants found the pressure they received to fundraise insensitive and insulting may exacerbate their feelings of being isolated and misunderstood, even by an organization that is supposed to be a major advocate for them. The mission statement of the NMSS is general but most of its activity is around education, awareness raising, and fundraising for research. How much direct service it aims to supply is unclear. Regardless, bloggers clearly felt that there are unmet needs which highlights a gap in institutional support services.

My initial conceptions of the “medical establishment” had been limited to direct service providers such as physicians, hospitals, and health insurance companies or the public health sector. Particularly because MS is not a contested or unrecognized illness, I overlooked the potentially politicized nature of many advocacy organizations. This emergent theme shed a different light on an important sector of the medical establishment where there may be a disconnect between the expectations people with MS might have of an advocacy organization and that organization’s goals and operations.

Summary

Blogging is simultaneously an empowering, disciplining, and resistant practice. The same mechanisms reproduce these practices, namely authoring public narratives about lived experience with illness and the consumption, generation, and dissemination of knowledge by patients. While narrative reproduces the rhetoric of self-responsibility and body governance, it also gives voice to otherwise unheard experiences, which can empower the patient to challenge the dominant power structure upon which contemporary medicine

in built. Likewise, the practices of self-educating, producing experiential knowledge, participating in producing data, and disseminating knowledge can empower the patient with information that can be used to help treat their condition and which may give them a sense of greater agency. At the same time, it reproduces the practice of body governance and self-discipline that benefits the state. More recently, the use of digital technologies is a key mechanism through which we perform this role.

In enacting these practices both *by* blogging and *through* blogging, they create and shape a mediated space through which to practice patient-hood. Rose and Novas's (2002) work has focused on biotechnologies of the body and has explored theoretical implications of an overarching neoliberal framework in which body governance is reproduced. Here, I have sought to apply their theoretical conceptions to the lived experience of chronic illness within the neoliberal state. What this study has revealed is that, in practice, biological citizenship is contradictory: the burdens envisioned by Rose and Novas may be welcomed by patients for whom more information helps them manage the everyday realities of living with chronic illness and navigate the systems in which they have little choice but to participate.

Conceptually, theories that take up body governance seek to call attention to the state's interest in a disciplined body, and how political, social, and cultural norms are scripted onto the body. These conceptions suggest a passive body, unaware or unconcerned with the forces working on it. Feminist theorists have sought to counter these assumptions by calling attention to how these forces are experienced. Indeed, my participants were very much aware of the interest in their bodies by a number of institutions: a health care system that simultaneously tries to treat, care for, regulate, profit

from, and deny care to them; a state that reluctantly supports them with meager resources; and a political and socio-cultural framework that compares their bodies to an idealized norm and constructs them as disabled, which sets standards of value, and which generates and reproduces a rhetoric of illness and disability within which they negotiate their lives.

If an idealized version of a participatory patient-hood could even be realized, which I argue is neither possible nor entirely desirable given the underlying structural inequalities that facilitate it, a constellation of factors would have to be in place: a patient who is willing and able to undertake self-education and knowledge-production; sufficient personal and social resources to enable them; digitally literacy and regular access to the internet; and a relationship with medical providers who both meets her needs and support patient engagement. The model of participatory patient-hood ignores the structural inequalities that strongly influence states of health, access to health care, and health outcomes. There are real potential benefits from the integration of health and social media and they could be used to address some of these disparities, assuming there are other structural supports in place. But to assume that simply constructing and promoting participatory patient-hood can bridge already-existing gaps without other interventions results in perpetuating inequalities in which some benefit from new technologies, while others miss out.

CHAPTER 7: CONCLUSION: MEDIATING VOICE & PATIENT-HOOD

“I wanted to put my voice into what was at that time a smaller community. I didn’t know what it would mean... Or if it was something I really wanted to do and it has become critical in my coping with the disease and learning that I can write well. It changed my life with MS.” - survey participant

Blogging is simultaneously an empowering, disciplining, and resistant practice. The same mechanisms reproduce these practices, namely authoring public narratives about lived experience with illness and the consumption, generation, and dissemination of knowledge by patients. While narrative reproduces the rhetoric of self-responsibility and body governance, it also gives voice to otherwise unheard experiences, which can empower the patient to challenge the dominant power structure upon which contemporary medicine is built. Likewise, the practices of self-educating, producing experiential knowledge, participating in producing data, and disseminating knowledge can empower the patient with information that can be used to help treat their condition and which may give them a sense of greater agency. At the same time, it reproduces practice of body governance and self-discipline that benefits the state. More recently, the use of digital technologies is a key mechanism through which we perform these roles.

Contributions of the study

Theoretically, conceptions of internet as part of everyday environments are still problematic in that they fail to capture the elusive in-betweenness, or interstitiality, that occupies a space somewhere between online and offline, and public and private. Most

theoretical conceptions of digital communication distance themselves from the “fleshy, messy stuff of everyday life” that Katz (2001, p. x) encourages in the study of lived experience. As most of the bloggers discussed, the transition between online and offline is relatively fluid but conscious decisions are made to include or exclude certain information and, I argue, less-conscious decisions to adhere to certain narrative parameters.

This study makes a number of contributions to the fields of environmental psychology, Internet studies, and women’s studies among other interdisciplinary fields, such as disability studies and critical human geography. First, few social scientists³⁵ have studied personal health blogs and to date, no studies have focused chronic illness specifically. Second, this study conceives of blogging as narratives about life with illness, rather than illness narratives, which warrants new analytical approaches. For example, it points out the unique characteristics and nuances of online narrative (such as the public-private nature of online social media; bloggers’ relationship to audience; construction of voice; etc.). Third, it supports literature that finds that blogs can be sites of meaningful engagement with others. Finally, it demonstrates that blogs are mechanisms of practicing patient-hood that both contest and reproduce in some ways patriarchal power structures in health care, and reshape patient-hood.

In the tradition of feminist scholarship, it is important to consider lived experience, especially in light of gendered practices that are reproduced online and the potential and limitations of the Internet to be an empowering space for challenging larger social

³⁵ There is a literature of applied studies in the fields of nursing, public health, and medicine. These largely explore the use of the Internet and/or social media as it impacts health care practice. For the purposes and scope of this study, however, they are only tangentially relevant.

structures and practices. The popular media, in general, often make the mistake of either assuming a neutral (male) user or not taking up the problem at all. Need further support for this

Limitations and implications for research methods

Research exploring social media can be approached in a number of ways through different locations on the Internet (in this case, blogs) and through different methods. By using three distinct methods, the ethnographic content analysis, the online survey, and the online discussion, I attempted to approach the area of study from multiple vantage points and these methods afforded valuable insight. As with all methods, however, these three had some limitations.

In studying public blogs, I chose subjects who openly share their personal viewpoint. This means that my findings are limited to the small minority of American women with MS who blog, and don't fairly represent the hundreds of thousands of American women with MS who do not blog publicly, or who may not use social media to connect to others with MS. However, drawing on the support of literature on illness narratives, some of the themes about living with illness were universal (such as describing physical symptoms and the disruption caused by illness, as well as describing strategies for working around limitations) and we can reasonably assume that at least some commonality is shared by bloggers and non-bloggers alike.

As public bloggers, these women may be more comfortable sharing their thoughts and stories and be predisposed to participate in a research project compared to private bloggers or non-bloggers. The high response rate to my survey (50% or n = 20) may be partially attributed to this comfort and openness. Likewise, a certain amount of self-selection probably contributed to both the willingness and enthusiasm of the nine bloggers who elected to participate in the third phase of participant online discussion.

The choice to create a private online forum (Phase 3) instead of studying a pre-existing forum was informed by three concerns. First, I did not want to be a 'lurker.' That is, I neither conducted research without forum participants knowing, nor did I insert myself into a pre-existing group and ask to conduct research, which could have made some participants uncomfortable and reluctant to share as they might otherwise. Second, it allowed the forum to be a more participatory research method. The forum was specific to this research project and participants opted-in. The purpose of the project was explained clearly to them and their feedback was solicited at several points during the collection period (see Appendix VI). Third, it was fully private, which many larger discussion forums are not. Only those who had an account and the password to the group could see any content or post any content. This protection was created to ensure confidentiality and create an environment in which participants could feel comfortable sharing sensitive information.

Nevertheless, it could be argued that creating a more selective, private, time-limited forum for participation could not replicate the more organic and fluid space of a larger, more inclusive, and open-ended forum. While participants were fully engaged and often posed their own questions or took the discussion in various directions, I was clearly the

administrator who had set up the parameters of the group. Also, the topical areas I asked them to discuss and the questions I posed were very specific to their identities as women with MS who blog, so the conversation rarely went too far astray of the questions and limited conversations about other issues.

While this research was intended to focus on the nature of online interactions, there are drawbacks to communicating exclusively online. It does not allow for the particular qualities of face-to-face interaction, including a synchronous flow of conversation, behavioral cues and settings, such as in their homes or the physical spaces where they blog. However, online research allows for geographic diversity and therefore creates a sample that would be difficult to obtain in person. As discussed extensively in the methodology, there is no way to accurately gauge the scope of or take a representative sample of blogs on the internet, so studies like this one explore phenomenon in a new context. However, using a sample of blogs that were almost all linked or cross-linked to each other forms a coherent collection from which to draw conclusions. While the sample was small (N=40, including a survey sample of n = 20 and a participatory discussion sample of n = 9), it was an in-depth study of very specific population and gains strength from thorough and multi-faceted approach. A study that included an in-person component, such as observing and interviewing bloggers in the situated context of their home, would likely better demonstrate the overlaps and integrations of online and offline better than a study conducted from only one side of the computer screen. Since I did not include individual interviews in my study design, it would be difficult to predict what might be gained or lost from taking this approach in a different setting. The collaboration and knowledge-building that resulted from the discussion would be lost, but a deeper, more thorough

understanding of an individual's experience might be gained. An in-person component would be particularly beneficial to use with bloggers who are not quite as comfortable with expressing themselves publicly, particularly when looking for silences and interrogating those.

As with the research methods themselves, I could have chosen several other ways to code and analyze data. For the ethnographic content analysis I analyzed a subset of three months, and further analyzed two entries per blog. By not analyzing entire blogs, or longer periods of time, I did not capture topics or events that happened outside of that time frame and did not capture a larger arc of the blogs over time. The three months and two discrete entries I focused on may not be truly representative of an individual blog as a whole or all of the blogs as a collection. Also, the frequency of blog posts on any given blog varies widely. This was clear from a general read of the blogs, and some of the bloggers commented on it themselves by noting how long it had been since they last blogged. Finally, I focused primarily on the text of blog entries and while I did take note of visual images (photos and graphics) and code those that were included in my smaller data set, I did not analyze elements of blogs such as formats and visual themes, graphics, and other media such as video. Nor did I focus on how the choice of software platforms could influence functions and elements of design and content. These elements form a rich data set that, in and of themselves, would greatly enhance further study.

The value in studying blogs is that it gives researchers direct access to bloggers' voices and studying them in aggregate allows us to capture a more holistic picture of a common experience such as illness. The challenges (described in Chapter 2) of studying the unwieldy 'blogosphere' remain, but projects such as this one that carve out niches in order

to understand the experience of individuals or a particular group, are not lessened by scale. In fact, I believe that the findings from this project could prompt more studies that explore other aspects of practicing patient-hood within a neoliberal context, such as the emerging trend of self-reporting health data to companies that aggregate and sell the data, and similar practices of performing unpaid labor.

I enjoyed the process of conceptualizing and shaping research methods, applying “traditional” methods to a digital field of study, and learning, testing (and sometimes rejecting) tools such as software programs. The use of online research methods to systematically collect data and analyze social phenomena is in its early stages. It’s exciting to contribute to a rapidly emerging and disparate field held loosely together by a medium. It is my hope that my future research, and the research of others will take lessons from these experimentations. As evidenced by the myriad of ways I could have approached this project methodologically, online projects can be viewed through a wide variety of lenses.

Finally, as Haraway (1988) and others posit, knowledges are situated, and my own positioning as a researcher influences my inquiry and the interpretation of my results. While I am sensitive to areas of bias, I am looking through the lens of privilege as a white, middle-class, educated woman who chose to pursue a Ph.D., with substantial experience navigating the health care system. At the outset, I described my life-long relationship to chronic and terminal illness, which inherently colors my perspective. Likewise, my own opinions about such topics as doctor-patient relationships and power structures in medicine, as well as a conflicted view of sharing personal experience on the Internet shape the arguments I make. However, one of the strengths of social science research that

considers the position of the researcher is that it both requires the researcher to be accountable for the work and provides the reader with contextual information.

There are several areas of scholarship and practice this dissertation does not take up, but which would benefit from the findings of this study. First, health care providers, patient advocates, advocacy groups, service organizations, and any persons or organizations with a direct role in the care and assistance of people with chronic illness could improve their understanding of the lived experience and perspective of their patients or clients, better assess needs, and evaluate their performance. This would be made much more effective if they involved the patients and clients themselves in the processes of designing and administering programs or developing policies. Similarly, public health campaigns and interventions could be made more effective by listening to the voices of chronically ill people and involving them in planning and programming. Especially now that social media is integrated into the majority of public health messaging, a better understanding of the ways that health information about managing and coping with chronic illness is shared could assist in developing more effective ways of disseminating information. Finally, this study could be applied to scholarship about health activism and epistemic communities (Akrich 2010), offering perspective on how communities are constructed through blogging and how lay expertise is developed using social media.

Suggestions for future research

Future research would address some of the methodological limitations, apply new methodologies, explore related areas and expand theoretical boundaries. Attempts to

expand methodologies or apply new ones might take up a more detailed analysis of the blogs, such as design and visual elements; themes and content over time; development of bloggers' knowledge over time; deeper analysis of links and cross-links to other blogs, etc. A longer participatory phase would allow relationships to grow among participants, and allow them greater freedom to shape the discussion. Preferably, this would be a forum that could carry on after the researcher left the project. Adding an offline component, such as in-person interviews with bloggers in their homes or everyday physical environments, would add valuable insight. This would better articulate the offline experience that, in this study, is mediated through the lens of online. This approach could offer a rich comparative perspective, not just between online and offline, but in the negotiation between the two. Future study could also explore other offline experiences related to blogging, such as attending blogging conferences or bringing bloggers together in person. To enhance the participatory approach of this study, future research might also take up a participatory "project" co-created with bloggers, such as a collaborative online resource, a collection of narratives, or an activist or advocacy project.

Much of the social science research on online illness narrative has focused on breast cancer as a central subject. This study contributes to the field by extending the area of study to include chronic illness. Applying the methodological approaches and/or research questions to other types of chronic illness, and other illness categories (such as mental illness or terminal illness) would further support and diversify the field of study. Also, examining blogs in relation to how other social media platforms are used by people with chronic illness to narrate their experience and connect to others would both expand methodologies into other areas, as well as add to cyber theoretical frameworks.

Incorporating the voices and experiences of those who do *not* blog would be informative for understanding the ways in which social media is perceived as a public illness narrative. The bloggers in my sample comprise a small minority of women with MS and many people intentionally do not participate in social media or may not share their experience with illness online. Hearing these perspectives may illuminate reasons people with MS may or may not choose to engage in social media in these ways. A comparison to the use of other social media, such as Facebook, or looking at activity on a constellation of social media sites, would demonstrate how illness experience is narrated (or not) on different platforms, particularly as some platforms fall out of favor and others emerge.

APPENDIX

I. List of blogs and URLs

II. Survey recruitment email

III. Blank survey

IV. Discussion recruitment email

V. Consent form

VI. Discussion introduction and questions from each week

VII. Coding Schema

VIII. Examples of Blogs (first page only)

Appendix I – List of Blogs Included in Ethnographic Content Analysis

Title of blog	Blog URL
Brass & Ivory: Life with MS & RA	http://www.brassandivory.org
Living Well with MS & Disabilities: Ellie's Blog	http://www.saratogaareas.com/ellie/blog1.php
Dancing with Monsters: Chronic Illness and Creative Transformation	http://dancingwithmonsters.blogspot.com
Living Day to Day with Multiple Sclerosis	http://livingdaytodaywithmultiplesclerosis.blogspot.com
Stuff Could Always Be Worse	http://stuffcouldalwaysbeworse.blogspot.com
Messy Stuff: A Life with MS and Other Ramblings	http://messystuffalifewithms.blogspot.com
Multiple Sclerosis and Me	http://msxats.blogspot.com
disAbled in San Francisco	http://peelister.blogspot.com
X-out MS	http://blog.xoutms.com
It is what it is, until it isn't what it once was	http://mkm55406.blogspot.com
A stellar life	http://dj-astellarlife.blogspot.com
Bifurcate in the road	http://kmilyun.com
Chain Reaction	http://mylifeisachainreaction.blogspot.com
Halt Stop Forget Relax	http://hsfr.blogspot.com
Kaleidoscope Muff	http://kaleidoscopemuff.blogspot.com
The Lesion Journals	http://thelesionjournals.blogspot.com
My New Normal	http://www.mynewnormals.com
Messy Minds	http://sherristakes.com
MS~LOL: Multiple Sclerosis a Life Of Learning	http://mslol.me

Say It Isn't So	http://insimpleterms.blogspot.com
MS Renegade	http://www.msrenegade.com
Down the MS Path	http://vvbms.blogspot.com
Grace_2_Wheel: My days with MS	http://grace2wheelmydayswithms.blogspot.com
Gumbo	http://gumboofblogs.blogspot.com
Living! With MS	http://ysestringer.blogspot.com
Brain Cheese	http://brain-cheese.blogspot.com
A Short in the Cord	http://shortinthecord.blogspot.com
Navigating the Journey of MS	http://www.navigatingthejourneyofms.blogspot.com
The Gimp Chronicles: Shade-Stealing Crips	http://tejasclubbie.blogspot.com
Turtle Speed	http://speedofturtle.blogspot.com
msrenaclare	http://msrenaclare.blogspot.com
Living with MS? Me too...let's talk	http://livingwithmsmetoo.blogspot.com
Sunny, With A Chance of Clouds	http://www.sunnywithachanceofclouds.com
My Journey with MS	http://myjourneywithms-kimberly.blogspot.com
Funky Mango's Musings	http://funky Mangos Musings.blogspot.com
Half Korean Girl with Internet Access	http://halfkoreangirlwithinternetaccess.blogspot.com
Just My Thoughts	http://mis0673.blogspot.com
Life Can Be Simple	http://lisadray.blogspot.com
Living With MS	http://lauren-livingwithms-aolcomlglbgl2003.blogspot.com

Appendix II – Recruitment email for the survey

Dear _____,

My name is Collette Sosnowy and I am a Ph.D. student in environmental psychology at the Graduate Center of the City University of New York. I'm conducting a research project for my dissertation about blogs written by women with Multiple Sclerosis.

For my research, I have been reading your blog and am very interested in what you and others are writing about life with MS. I'd like to learn more about why you blog and how blogging fits into your life.

I'd like you to complete a brief online survey about these topics. The link to the survey is at the bottom of this email. The survey is anonymous, so your identity will be protected. The information you share will contribute to a greater understanding of the role of blogging in the lives of people with chronic illness.

The survey will take approximately 10-15 minutes to complete. I hope you will complete the whole survey, but you may choose to skip any questions that may make you uncomfortable and you can quit the survey at any time.

I really appreciate your participation! Please feel free to ask me any questions by e-mailing me at csosnowy@gc.cuny.edu.

You can also learn more about me and the project by visiting my website <http://nml.cuny.edu/collettesosnowy>

Thank you!

Here's the link:

<http://edu.surveygizmo.com/s3/778690/0200f41af155>

Appendix III – Survey

A Research Project About Multiple Sclerosis Blogs

Thank you for agreeing to take this survey! As I mentioned in the email, the survey will take approximately 15 minutes to complete. I hope you will complete the whole survey, but you may choose to skip any questions that may make you uncomfortable and you can quit the survey at any time. The survey is anonymous. The information you share will contribute to a greater understanding of the role of blogging in the lives of people with chronic illness. By taking this survey, you certify that you are at least 18 years old.

1. What are some of the things that motivate you to blog? Please choose the three most important:

- | | |
|--|---|
| <input type="checkbox"/> daily events | <input type="checkbox"/> medications |
| <input type="checkbox"/> my interests or activities | <input type="checkbox"/> medical treatments |
| <input type="checkbox"/> my family and friends | <input type="checkbox"/> alternative treatments |
| <input type="checkbox"/> my pet(s) | <input type="checkbox"/> diet and exercise |
| <input type="checkbox"/> how I'm feeling physically (symptoms, etc.) | <input type="checkbox"/> mobility (getting around; using devices like chairs, canes, ramps, etc.) |
| <input type="checkbox"/> how I'm feeling emotionally | <input type="checkbox"/> being diagnosed with MS |
| <input type="checkbox"/> coping with MS | <input type="checkbox"/> news about MS, like new medical research, new treatments, etc. |
| <input type="checkbox"/> things that inspire me | <input type="checkbox"/> sharing information about MS |
| <input type="checkbox"/> things that bother me | <input type="checkbox"/> advocacy efforts such as fund-raising, activism, policy efforts, etc. |
| <input type="checkbox"/> doctor and hospital visits | <input type="checkbox"/> other (please describe) |

2. Why did you start your blog?

3. On average, how often do you post on your blog?

- daily
 - a few times a week
 - once a week
 - a few times a month
 - once a month
 - every few months
 - every 6 months or longer
-

4. About how much time does it take for you to write a blog post (including any preparation or research)?

- less than 30 minutes
 - 30 minutes to an hour
 - more than an hour
 - more than two hours
 - it varies
-

5. If so, why?

6. Who do you think reads your blog? (check all that apply)

- my family and friends
 - other people with MS
 - other MS bloggers
 - family and friends of people with MS
 - a general audience
 - other patients who do not have MS
 - medical professionals
 - people with an interest in health issues and health policy
 - industry representatives (such as from insurance companies, drug companies, marketers, etc.)
 - other (please specify)
-

7. What do you hope your readers get from reading your blog?

8. How often do you read other blogs about MS?

- often
 - sometimes
 - rarely
 - never
-

9. How often do you comment on other people's blogs about MS?

- often
- sometimes

- rarely
 - never
-

10. How often do readers comment on your blog?

- often
 - sometimes
 - rarely
 - never
-

11. About how often do you post on other MS-related websites (such as discussion forums, social networking websites, etc.)?

- daily
 - a few days a week
 - once a week
 - once a month
 - occasionally (less often than once a month)
 - rarely
 - never
-

12. Do you feel connected to other MS bloggers? If so, please explain.

13. Does blogging allow you to do things you might otherwise not be able to do?

- yes
- no

14. If yes, in what ways?

15. How do you think you would feel if you were not able to blog?

About you

Some basic information about you will help us understand the demographics of bloggers.

16. How long have you been diagnosed with MS?

17. How old are you?

18. What is your race or ethnicity?

- white
- black
- hispanic or latino
- asian
- other (please specify)

19. What is your educational background?

20. Do you live in a:

- urban area
- suburban area
- small town
- rural area

21. Which best describes how you spend your time? (check all that apply)

- I work full time
- I work part time
- I am a stay-at-home mom
- I am retired
- I am not currently working due to disability
- I am not currently working for reasons other than disability
- I am involved in MS advocacy work
- My family keeps me busy
- I am involved with my community, church, etc.
- I spend time with my friends
- other (please explain)

22. Please tell me about your household (who do you live with? do you have children or grandchildren?).

23. I would like to contact you about participating in an online discussion with other MS bloggers. If you are willing to be contacted, please provide your email address.

24. Is there anything you would like to add?

Thank you for taking the survey!! If you have any questions, please contact me at csosnowy@gc.cuny.edu

Appendix IV – Recruitment Email for Discussion

Dear _____,

Thank you very much for taking the survey and permitting me to contact you with a follow-up! I'd like to invite you to participate in an online discussion forum with about 10 other bloggers. The discussion will take place over the course of 3 weeks beginning Monday, April 9th. I will post a few questions at the beginning of each week and I will ask you to post to the discussion at least twice a week. How much time you spend participating in the discussion will vary, based on how often you choose to write, but please expect to spend at least 30 minutes per week. Just to clarify, this isn't a live chat, it's a discussion forum that you can post to when you choose. The discussion will take place on a password-protected website, so it will not be seen by anyone outside the group. Also, your identity will be kept confidential. I will explain more about this but would first like to see if you would be interested in being part of the project. Please let me know if you would be interested in participating and, of course, I'd be happy to answer any questions you might have.

Thanks very much!

Collette Sosnowy
csosnowy@gc.cuny.edu
collettesosnowy.org

Appendix V – Consent Form

The Graduate Center of the City University of New York

Psychology Department

PARTICIPANT CONSENT FORM

I discussed many of the aspects of the project in my previous email, but this consent form goes into greater detail. Also, it is required by my university to have written permission from all study participants.

As mentioned, my name is Collette Sosnowy and I am student in the Psychology Ph.D. Program at The Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled “Personal Health Blogs and Participatory Medicine.” This is a research study about personal health blogs written by women with Multiple Sclerosis. The study is expected to contribute to research about the use of the Internet, specifically blogs, by patients with chronic illness.

In reading your blog, I have been very interested in what you write there and would like to know more about what it's like having MS and why you blog about it. I would like to invite you to participate in an online discussion with 10-12 other bloggers. The discussion will take place over the course of 3 weeks beginning (date), and I will ask you to write at least twice a week. The time of your participation will vary, based on how often you choose to participate in the discussion, but please expect to participate for at least 30 minutes per week.

The discussion will take place on a password-protected website. All of your answers will be kept confidential from anyone outside of the group, myself, and my advisors. Once the discussion is over, I will archive the data in a password-protected file to which only I, and my advisors, will have access. I will then remove the content of the website from the Internet.

I will provide you with a password you will use to sign in each time you enter the site. You will choose your username. I may quote one of your answers or discuss something you said. If so, I will use your username, so please choose one that you feel comfortable being identified with. If you would like to use your real name as your username, please feel free to do so, but know that it may be published.

For another part of the project, I will be looking at a large number of blogs, including yours. Because these blogs can be considered public content, I may discuss them and use the blog's real name. Although your blog may be part of the larger sample, I will NOT explicitly link your username and your comments from the discussion with the name of your blog.

Once completed, this dissertation will be publicly available through an academic database. I may also publish results of the study elsewhere.

The risks from participating in this study are no more than encountered in everyday life. The benefit of your participation is that you will be contributing to developing further knowledge about bloggers with chronic disease. You may also enjoy sharing your perspective with other bloggers in our mutual learning process. However, you may refuse to answer any of the questions and may withdraw from the study at any time.

If you have any questions about this research, you can contact me at (484) 949-4408 or c_sosnowy@yahoo.com, or my advisors Cindi Katz at (212) 817-8728 ckatz@gc.cuny.edu or Joan Greenbaum at (212) 543-0460 or jgreenbaum@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu.

Thank you for your participation in the study. I will give you an electronic copy of this form. If you would like a copy of the study, I'd be happy to email it to you once it is complete.

[electronic signature]

Participant's signature

Date

Investigator's signature

Date

Appendix VI – Discussion introduction and questions from each week

Introduction to Discussion & Week 1 Questions

Before we begin, I'd like to give you a brief summary of the survey you all took. I received 20 responses from the 40 bloggers I sent it to and the results were very interesting. You reported several reasons for starting your blogs. Most importantly, you enjoy writing...and not just about MS, but many things about your life, experiences, interests, etc. Some of you want to educate others and share information about MS, some want to write about everyday life with MS, and some don't want to write about MS at all.

Many of you read each others' blogs and sometimes comment on them. When I asked if you feel connected to other MS bloggers, about 2/3 of you said yes, and 1/3 said no. Many of you said that blogging allows you to do things you might not otherwise be able to do, especially to share, vent, and put your voice 'out there,' and that blogging makes you feel more connected, less alone, and that it's an 'outlet.'

To start, please tell us a little bit about yourself!

The questions I'd like for us to discuss are:

What are your thoughts about being part of the MS 'blogosphere'? Is it important for you to feel connected to other MS bloggers or other people with MS? Why or why not?

Where else do you feel connected to others in your life? If you feel a

connection to others online, how are these relationships different from your 'offline' ones?

Week 2 Questions

Hi Bloggers,

Welcome to Week 2! As with the last thread, my questions are intended as conversation starters. This week I'd like to get your perspective on being a "medical patient" with MS.

Some people say that expectations of people who are patients have changed over the past few decades. In the past, people were expected to accept doctors' advice and treatments without questioning them, but things have changed. Now, you may be expected to do a lot of things that people used to rely on their doctor for (such as educate yourselves about your illness, stay up to date on new developments in drugs, treatments, and medical research, and deal with things like insurance companies and disability benefits).

Some people think that these changes empower patients. Others think they place too much of a burden on patients.

What do you think?

Questions for Week 3

Hello bloggers,

Thank you for keeping such an interesting discussion going! I'm learning a lot from sharing with each other and hope you are too.

So far we've talked about blogging and what it's like to be a patient with MS. I'm interested in learning about how our online lives and offline lives overlap. Many researchers treat online and offline as separate, but I think it's clear that they often blend in our everyday lives. More specifically, I'm interested in talking about how we experience our physical bodies and how we talk about them online.

How do your online and offline lives overlap and how are they different?

What else is going on around you when you blog, such as do you have a favorite place to write, a particular time of day or a routine that you like to follow? Please describe the setting.

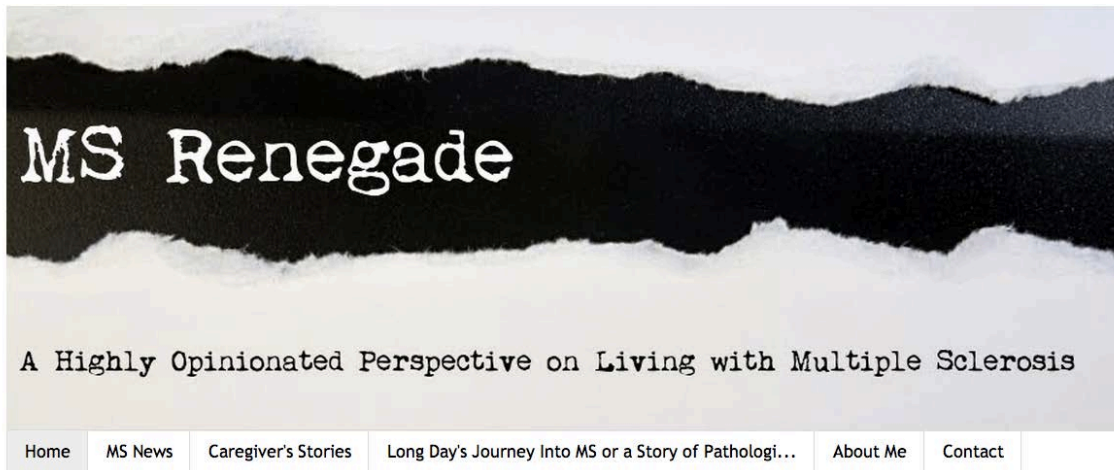
Are there things about your offline life or about having MS you don't blog about? Why or why not?

Remember, we are a closed discussion group and have built up a rapport, but of course, only share what you are comfortable with.

Appendix VII - Example of schema of descriptive data

		Sheets		Charts		SmartArt Graphics										WordArt											
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	V	W	X				
	Blog URL	Title of blog	Bio		Total # of posts	Date	blog site	Blogs	elsewh	Race	Mari	Chilc	Pets	Age	Se	En	PT	Ge	Sub	Concurrent	c	Blog archive	Blogroll	Host	Paid Ads	Blog awards	
1	Note																										
2																											
3																											
4																											
5	http://www.brassandivory.org/	Brass & Ivory: Life with	Multi-part story of diagnosis;		1055	Aug-07	HealthCentral	W	DP	N					S	Y	VA		RA		Y	Y		Blogger	N	N	
6	http://www.saratoqaareas.com/	Living Well with MS & D	Y; in header		102	Jun-08		W	M	Y					75	S	N	Ret	NY		Y	N		http://www.:	Y	N	
7	http://dancingwithmonsters.bl	Dancing with Monsters:	Y; sidebar		85	Jun-07	other blog; jo	W	M	Y					S	Y	PT	MN			Y	Y		Blogger	N	N	
8	http://livingdaytodaywithmsbl	Living Day to Day with I	Y; sidebar		182	Apr-09		W	M	Y					S	Y					Y	Y		Blogger	N	Y	
9	http://stuffowdshewsdworse	Stuff Couid Always Be V	Y; page		485	Dec-08		W	M	Y	Y				S	N	GA				Y	Y		Blogger	N	but offers t	
10	http://messystuffalifeithms.b	Messy Stuff: A Life with	Y; in About Me		430	Aug-08		D	N	Y					S	Y					Y	Y		Blogger	N	Y	
11	http://mexalts.blogspot.com/	Multiple Sclerosis and M	Y; sidebar & header		256	Nov-09		B										GA			Y	Y		Blogger	N	Y	
12	http://zeesuper.blogspot.com/	disabled in San Francis	Y; page			Jan-10		W	D	Y	Y				S	N	CA				Y	Y		Blogger	N	N	
13	http://biops.xoutms.com/	X-out MS	Y; header		75	Feb-09		W	M	Y					S	Y	CA				Y	N		Blogger	N	N	
14	http://mkm53406.blogspot.co	It is what it is, until it is	Y; page		100	Oct-10		W			Y							MN			Y	N		Blogger	N	Y	
15	http://dl-astelife.blogspot.c	A stellar life	Y; sidebar		2160	Aug-07		W	DP	N					54	G	Y	WA			Y	Y		Blogger	N	Specifically	
16	http://kmbvua.com/	Bifurcate in the road	Y; page			Dec-05		W			Y				53			CA			N	Y		Wordpress	N	N	
17	http://mylifechainreaction.b	Chain Reaction	Y; sidebar		98	Aug-08		W			Y							TN			Y	N		Blogger	N	N	
18	http://hsfr.blogspot.com/	Halt Stop Forget Relax	Y; sidebar		307	Aug-08		M	N	Y					56	S		WA			Y	Y		Blogger	N	Y	
19	http://kaleidoscopepuff.blogg	Kaleidoscope Puff	Y; sidebar		452	Oct-09		M	Y						S	N	NJ				Y	Y		Blogger	N	Y	
20	http://thelesionjournals.blog	The Lesion Journals	Y; page		69	Dec-09		W										CA			Y	Y		Blogger	N	Y	
21	http://www.mynewnormals.co	My New Normal	Y; page		45	Feb-11	National MS Si	B	M	Y								LA			Y	Y		Blogger	Y	(sponsors)	
22	http://sherristakes.com/	Messy Minds	Y; sidebar		?			W	M	Y					S	Y	TX				Y	Y		Wordpress	Y	N	
23	http://misl.ca/	MS-LOL: Multiple Scien	Y; sidebar			May-07		W							S						Y	Y		Wordpress	Y	N	
24	http://ms.mscietems.blogspot	Say It Isn't So	Y; sidebar		61	Nov-11		W													Y	Y		Blogger	N	N	
25	http://www.msrenegade.com/	MS Renegade	Y; sidebar		24	Sep-10	other blogs: http://hourishourselves.blogspot.com & I	NJ													Y	Y		Blogger	Y	Y	
26	http://vvvms.blogspot.com/	Down the MS Path	Y; sidebar		443	Jan-06		W	Wdc	Y					S		TX				Y	Y		Blogger	Y	Y	
27	http://graceandwheelsdaysaith	Grace, 2 Wheel: My day	N		93	Mar-09		W	M						S		OR				Y	Y		Blogger	N	N	
28	http://gumboflogs.blogspot.c	Gumbo	Y; sidebar		54	Apr-09		W	M	Y					S										Blogger	N	Y
29	http://yestringers.blogspot.co	Living! With MS	N		352	May-08		W										CO			Y	Y		Blogger	N	Y	
30	http://brain-cheese.blogspot.c	Brain Cheese	Y; sidebar		729	Mar-06												WA			Y	Y		Blogger	N	Y	
31	http://shortintheord.blogspot	A Short In the Cord	Y; page		?	Aug-08	theMSShoppe.com								47			DE			N	Y		Blogger	N	Y	
32	http://www.navigatngthejour	Navigating the Journey	N		475	Aug-08	theMSShoppe.com											WI			Y	Y		Blogger	Y	N	
33	http://teasubbie.blogspot.co	The Gimp Chronicles: SP	Y; sidebar		169	Oct-06				N	Y				41	Y	AZ				Y	Y		Blogger	N	N	
34	http://speedofurtle.blogspot.c	Turle Speed	Y; page		17	Oct-11									24		WI				Y	Y		Blogger	Y	N	
35	http://msrenewcare.blogspot.c	msrenewcare	Y; sidebar		0	Feb-12	memoir	W										TX			Y	N		Blogger	N	N	
36	http://livingwithmsmetoo.blog	Living with MS? Me too.	Y; sidebar & header		?			W	DP	Y								VA			N	Y		Blogger	N	Y	
37	http://www.sunnywithachance	Sunny, With A Chance o	Y; sidebar		124	Jun-10		W							29	Y	PA				N	N		Blogger	N	N	
38	http://myjournevithms-kombi	My Journey with MS	Y; sidebar		396	Jul-08		W	M	Y	Y				S		CA				Y	Y		Blogger	N	Y	
39	http://funnymangosmusings.bl	Funny Mangos Musings	Y; sidebar		60	Feb-11		W										England			Y	Y		Blogger	N	N	
40	http://halfkoreanqirlwithintern	Half Korean Girl with Int	Y; header		48	Jun-10		A		Y					S	Y	FL				Y	Y		Blogger	N	N	
41	http://mis0673.blogspot.com/	Just My Thoughts	Y; sidebar		54	Oct-08									39		MI				Y	Y		Blogger	N	Y	
42	http://lifeisay.blogspot.com/	Life Can Be Simple	Y; header		0	Jan-12												N	Ret	TN	Y	Y		Blogger	N	Y	
43	http://lauren-ivnewithms-ak	Living With MS	Y; sidebar			Aug-06		W										Y	CA		Y	N		Blogger	N	N	
44																											

Appendix VIII – Examples of blogs (first page only)



THURSDAY, FEBRUARY 7, 2013

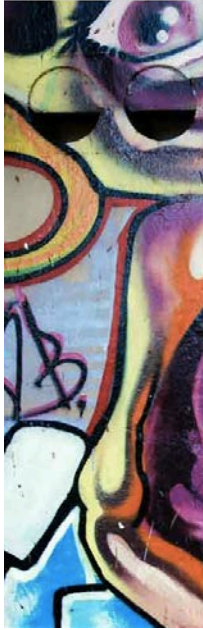


Desperately Seeking Breathing

This is cross-posted from my Nourish blog, to keep you up to date. My health took a turn for the worse last Fall. This post was published 11/8/12:

Last week, while we were all already dealing with a terrifying hurricane and no power for days, I began experiencing dramatic shortness of breath after only taking a few steps. I struggled and struggled, trying to convince myself it was just something I was imagining, even though I was taking deep, prolonged gasps for air with the least bit of exertion. I was





Grace_2_Wheel: My days with MS

Sunday, January 27, 2013

Weighty Issues

I always love the part of fantasy sagas where the protagonist encounters a riddle or puzzle that seems unsolvable and then, Voila, an answer is cleverly determined and the next stage of the Journey is revealed. A classic example of this is found in the Lord of the Rings trilogy in the scene with the sealed door, the monster in the lake, and finally, inspiration, the door swings open and the band of travelers is saved. I am in need of such clever insight, magic incantations, and clarity myself right now.

Since the failed bladder reroute surgery this past October my life is more topsy-turvy than anything else. I've written posts about it on this blog. To be truthful I am sick to death of living with the constant struggle of bag failures, urine soaked bedding and clothes, and having to lie still. The big problem: no the obese problem is what to do to repair the surgery that didn't work.

The surgeon is a great doctor. But, like many many many people he has a tremendous bias against the obese. And is incapable of factoring MS disability into the mix. He owns up to his own error in not doing a preoperative scan of my abdomen that would have prevented this entire mess. But that is looking backward. His solution now? Is for me to lose and forever maintain a total weight loss of at least 100lbs. He says with a supercilious smile, "If you want it badly enough, sacrifices will have to be made," and later in the conversation, "I see a 5'4" 125lb woman inside your body."

I have lived my entire adult life as a fat woman in a world that thinks less of me based on one glance. No one who isn't fat can begin to comprehend what that is like. No one who isn't fat can imagine the Sisyphean struggle that plays out nakedly on a public stage with every attempt to change. The kudos when you lose, the silent contempt when you fail. I was training to walk the Portland Marathon when MS hit the hardest. I still grieve that loss. For the next 12 years

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 - ▼ January (3)
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 - [Best Post Comment Ever: In 3D No Less](#)
- 2012 (17)
- 2011 (10)
- 2010 (36)
- 2009 (47)



Living Day to Day with Multiple Sclerosis

Living with Multiple Sclerosis is a daily battle. MS is the invisible disease or at least for most people. We fight many emotional and physical symptoms all the time. We need as much support as we can get. However due to the invisible symptoms we tend to not get a lot of support and that brings on more emotional stress which in return brings on more MS symptoms. A Vicious cycle.

Monday, February 13, 2012

Where Did I Go?? Journal 3 Entry



I have spent a lot of time thinking over the past couple months. Trying to figure out where things went wrong, when did all of this start, how could I have gone so deep into a hole and nobody see it? Then I realized it didn't matter, what matters most is getting better. It is very frustrating to me that it doesn't change or can get fixed fast enough. At times I feel like I am in such a very deep, lonely, hole that only I can get myself out of. It is very hard having a Multiple sclerosis, a disease that causes so many symptoms that are invisible to others. That alone makes you feel very lonely and frustrated. Comments that are made all the time like "At least it's not Cancer", "You are just being

About Me



Living Day to Day with Multiple Sclerosis

My name is Tara. I have been married for 18 years. We have 3 children. I was diagnosed with Multiple sclerosis in March of 2007 and what a whirlwind it has been. I think I went from a "Type A" personality to a "Type Z" personality. It's like life started over for me and I have to learn who the new me is while life continued for the rest of the world and they think I am the same old me.

[View my complete profile](#)



REFERENCES

- Agger, B. (2012). *Oversharing: Presentations of Self in the Internet Age* (1st ed.). New York: Routledge.
- Akrich, M. (2009). From Communities of Practice to Epistemic Communities: Health Mobilizations on the Internet. *Sociological Research Online*, 15(2), 10.
- Albanesius, C. (2010). Consumers Haven't Learned Not to Divulge Private Info Online. *PC Magazine*, 29(6).
- Altheide, D. (1987). Ethnographic Content Analysis. *Qualitative Sociology*, 10(1), 65–77.
- Bar-Lev, S. (2008). "We Are Here to Give You Emotional Support": Performing Emotions in an Online HIV/AIDS Support Group. *Qualitative health research*, 18(4), 509–521.
- Bauerlein, M. (2009). *The Dumbest Generation: How the Digital Age Stupefies Young Americans and Jeopardizes Our Future*. New York: Jeremy Tarcher.
- Belkin, L. (2011, February 23). Heather Armstrong, Queen of the Mommy Bloggers. *The New York Times*. Retrieved from <http://www.nytimes.com/2011/02/27/magazine/27armstrong-t.html>
- Berger, M., Wagner, T. H., & Baker, L. C. (2005). Internet use and stigmatized illness. *Social Science & Medicine*, 61(8), 1821–1827.
- Boston Women's Health Collective. (1971). *Our Bodies, Ourselves*.
- boyd, danah. (2006). A Blogger's Blog: Exploring the Definition of a Medium. *Reconstruction*, 6(4).
- boyd, danah. (2013). Networked Privacy. *Surveillance & Society*, 10(3/4), 348–350.
- Brenner, J. (2012). *Pew Internet: Social Networking (Commentary)*. Retrieved from: <http://pewinternet.org/Commentary/2012/March/Pew-Internet-Social-Networking-full-detail.aspx>
- Brown, P. (1995). Naming and Framing: The Social Construction of Diagnosis and Illness. *Journal of Health and Social Behavior*, 35, 34–52.
- Brown, P., Morello-Frosch, R., Zavestoski, S., Senier, L., Gasior Altman, R., Hoover, E., ... Adams, C. (2011). Health Social Movements: Advancing Traditional Medical Sociology Concepts. In B. A. Pescosolido (Ed.), *Handbook of the Sociology of Health, Illness, and Healing*. New York: Springer.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of health & illness*, 26(1), 50–80.
- Bullingham, L., & Vasconcelos, A. C. (2013). "The presentation of self in the online world": Goffman and the study of online identities. *Journal of Information Science*. 39(1): 101-112.
- Burke, M., Kraut, R., & Marlow, C. (2011). Social capital on facebook: differentiating uses and users.

- In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 571–580). New York: ACM.
- Cacioppo, J. T., & Patrick, W. (2009). *Loneliness: Human Nature and the Need for Social Connection* (Reprint.). W. W. Norton & Company.
- Carr, N. (2011). *The Shallows: What the Internet Is Doing to Our Brains*. New York: W. W. Norton & Company.
- Castells, M. (1996). *The Rise of The Network Society* (Vol. 1). Oxford: Blackwell.
- Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers, NJ: Rutgers University Press.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (1st ed.). Thousand Oaks, CA: Sage Publications.
- Collins, P. H. (2000). *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment* (2nd ed.). New York: Routledge.
- Conrad, P. (2008). The Shifting Engines of Medicalization. In P. Brown (Ed.), *Perspectives in Medical Sociology* (pp. 104–117). Long Grove, Illinois: Waveland Press Inc.
- Cooter, R. (2000). *Medicine in the 20th Century*. New York: Taylor & Francis.
- Crawford, R. (1977). You are dangerous to your health: the ideology and politics of victim blaming. *International journal of health services: planning, administration, evaluation*, 7(4), 663–680.
- Crawford, Robert. (1980). Healthism and the Medicalization of Everyday Life. *International Journal of Health Services*, 10(3), 365–388.
- Crawford, Robert. (2006). Health as a meaningful social practice. *Health*, 10(4), 401–420.
- D’Arcy, J. (2012, January 26). PunditMom breaks down the political evolution of mommy bloggers. *The Washington Post - Blogs*. Retrieved from http://www.washingtonpost.com/blogs/on-parenting/post/punditmom-breaks-down-the-political-evolution-of-mommy-bloggers/2012/01/25/gIQADz3PRQ_blog.html
- Daniels, J. (2009a). *CyberRacism: White Supremacy Online and the New Attack on Civil Rights*. Lanham, MD: Rowman & Littlefield Publishers Inc.
- Daniels, J. (2009b). Rethinking Cyberfeminism(s): Race, Gender and Embodiment. *Women’s Studies Quarterly*, 37(1/2), 101–124.
- Daniels, J. (2012). Case Study: Web 2.0, Healthcare Policy and Health Activism. In D. Nickitas, D. J. Middaugh, & N. Aries (Eds.), *Policy and Politics for Nurses and Other Health Professionals* (pp. 277–285). Sudbury, MA: Jones and Bartlett Publishers.
- DasGupta, S., & Hurst, M. (Eds.). (2007). *Stories of Illness and Healing: Women Write Their Bodies*. Kent, OH: Kent State University Press.
- Dingwall, R., Rafferty, A. M., & Webster, C. (2002). *An Introduction to the Social History of Nursing*. New York: Routledge.

- Ehrenreich, B. (2001, November). Welcome to Cancerland. *Harper's Magazine*.
- Ehrenreich, B. (2009). *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America*. New York: Metropolitan Books/Henry Holt.
- Ehrenreich, B. (2010, Spring). Smile! You've got cancer. *The Guardian*. Retrieved from <http://www.guardian.co.uk/lifeandstyle/2010/jan/02/cancer-positive-thinking-barbara-ehrenreich> on
- Ehrenreich, B. (2011). *Complaints and disorders: the sexual politics of sickness* (2nd ed.). New York: Feminist Press.
- Ehrenreich, B., & English, D. (1978). *For Her Own Good : 150 Years of the Experts' Advice to Women*. Garden City, N.Y.: Anchor Press.
- Ehrenreich, B., & English, D. (2010). *Witches, Midwives, and Nurses: A History of Women Healers* (2nd ed.). New York: The Feminist Press at CUNY.
- Emerson, R. M. (1962). Power dependence relations. *American Sociological Review*, 27, 31–41.
- Enns, C. Z. (2004). *Feminist theories and feminist psychotherapies: Origins, themes, and diversity* (2nd ed.). Binghamton, NY: Haworth Press.
- Epstein, S. (1991). Democratic Science? AIDS Activism and the Contested Construction of Knowledge. *Socialist Review*, 21(2), 35–64.
- Epstein, S. (1996). *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Epstein, S. (2000). Democracy, Expertise, and AIDS Treatment Activism. In D. Kleinman (Ed.), *Science, Technology, and Democracy* (pp. 15–32). Albany: State University of New York Press.
- Epstein, S. (2009). *Inclusion: The Politics of Difference in Medical Research*. Chicago, IL: University of Chicago Press.
- Eytan, T. (2008, June 13). The Health 2.0 definition: Not just the Latest, the Greatest! *Ted Eytan, MD e-health. patient empowerment. diversity.*. Retrieved from <http://www.tedeytan.com/2008/06/13/1089>
- Faden, R. R., & Beauchamp, T. L. (1986). *A History and Theory of Informed Consent*. New York: Oxford University Press.
- Fine, M., & Asch, A. (1988). *Women With Disabilities*. Philadelphia, PA: Temple University Press.
- Fiscella, K., Franks, P., Gold, M. R., & Clancy, C. M. (2000). Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. *JAMA: the journal of the American Medical Association*, 283(19), 2579–2584.
- Fisher, J. A. (2007). Coming Soon to a Physician Near You: Medical Neoliberalism and Pharmaceutical Clinical Trials. *Harvard health policy review : a student publication of the Harvard Interfaculty Initiative in Health Policy*, 8(1), 61–70.
- Foucault, M. (1980). *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. (C.

- Gordon, Ed.). New York: Pantheon.
- Foucault, M. (2003). *The Essential Foucault: Selections from the Essential Works of Foucault, 1954-1984*. (P. Rabinow & N. Rose, Eds.). New York: The New Press.
- Foucault, M., Ewald, F., Fontana, A., & Davidson, A. I. I. (2009). *Security, Territory, Population: Lectures at the Collège de France 1977--1978*. (G. Burchell, Trans., M. Senellart, Ed.) (1st ed.). New York: Picador.
- Fox, N., & Ward, K. (2006). Health identities: from expert patient to resisting consumer. *Health*, 10(4), 461–479.
- Fox, S. (2011). *The Social Life of Health Information*. Pew Internet & American Life Project.
- Frank, A. W. (1997). *The Wounded Storyteller: Body, Illness, and Ethics* (1st ed.). Chicago, IL: University Of Chicago Press.
- Frese, F. J., & Davis, W. W. (1997). The consumer–survivor movement, recovery, and consumer professionals. *Professional Psychology: Research and Practice*, 28(3), 243–245.
- Frese, F. J., & Myrick, K. J. (2010). On consumer advocacy and the diagnosis of mental disorders. *Professional Psychology: Research and Practice*, 41(6), 495–501.
- Gabriel, Y. (2004). *Myths, Stories, and Organizations: Premodern Narratives for Our Times*. New York: Oxford University Press.
- Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, 14(3), 1–32.
- Gibson, J. J. (1979). *The Ecological Approach to Visual Perception*. Boston: Houghton Mifflin.
- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Brunswick, NJ: Aldine Transaction.
- Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday.
- Gosling, J. (2008). Towards a Scientific Model of Disability. *Abnormal*. Retrieved from <http://www.ju90.co.uk/nimr/model.htm>
- Green, R. M. (2006). Unpacking “I Don’t Want It” - why novices and non-users don’t use the Internet. *First Monday*, 11(9).
- Greenbaum, J., & Kyng, M. (1991). *Design at work: cooperative design of computer systems*. Hillsdale, NJ: Lawrence Erlbaum Associates, Incorporated.
- Greenbaum, Joan. (2004). *Windows on the Workplace: Technology, Jobs, and the Organization of Office Work*. New York: Monthly Review Press.
- Gruys, K. (2012). Does This Make Me Look Fat? Aesthetic Labor and Fat Talk as Emotional Labor in a Women’s Plus-Size Clothing Store. *Social Problems*, 59(4), 481–500.
- Haraway, D. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*, 14(3), 579–599.
- Haraway, D. (1991). A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late

- Twentieth Century. In *Simians, Cyborgs and Women: The Reinvention of Nature* (pp. 149–181). New York: Routledge.
- Harvey, D. (2007). *A Brief History of Neoliberalism* (1st, First Edition.). New York: Oxford University Press.
- Henning, J. (2003). *The Blogging Iceberg: Of 4.12 Million Hosted Weblogs, Most Little Seen, Quickly Abandoned*. Perseus Development Corporation. Retrieved from <http://www.perseus.com/blogsurvey/iceberg.html>
- Herring, S.C., Scheidt, L. A., Bonus, S., & Wright, E. (2004). Bridging the gap: a genre analysis of Weblogs. In *Proceedings of the 37th Annual Hawaii International Conference on System Sciences, 2004*. Presented at the Proceedings of the 37th Annual Hawaii International Conference on System Sciences.
- Herring, Susan C. (2010). Web content analysis: Expanding the paradigm. In J. Hunsinger, M. Allen, & L. Klastrup (Eds.), *The International Handbook of Internet Research* (pp. 233–249). Berlin: Springer Verlag.
- Hochman, D. (2005, January 30). Mommy (and Me). *The New York Times*. Retrieved from <http://www.nytimes.com/2005/01/30/fashion/30moms.html>
- Hookway, N. (2008). "Entering the Blogosphere": Some Strategies for Using Blogs in Social Research. *Qualitative Research*, 8(1), 91–112.
- Medical News Today*. How Many Americans Have Multiple Sclerosis? No One Knows With Absolute Certainty. (n.d.). Retrieved from <http://www.medicalnewstoday.com/releases/40510.php>
- Hutchinson, R. (2001). Dangerous Liaisons? Ethical Considerations in Conducting Online Sociological Research. In *Conference Proceedings TASA 2001: The Australian Sociological Association*. Retrieved from http://64.233.179.104/scholar?hl=en&lr=&client=safari&q=cache:8D2rQxywgk8J:www.tasa.org.au/members/docs/2001_12/Hutchinson.pdf+related:8D2rQxywgk8J:scholar.google.com/
- Josefsson, U. (2005). Coping with Illness Online: The Case of Patients' Online Communities. *Information Society*, 21(2), 133–153.
- Joshi, P. (2011, March 14). Advertisers Seek to Harness the Power of the Mom Blogger. *The New York Times*. Retrieved from <http://www.nytimes.com/2011/03/15/business/media/15adco.html>
- Jurgenson, N. (2012, July 9). We Need a Word for That Thing Where a Digital Thing Appears in the Physical World. *The Atlantic*. Retrieved from <http://www.theatlantic.com/technology/archive/2012/07/we-need-a-word-for-that-thing-where-a-digital-thing-appears-in-the-physical-world/259570/>
- Kaironz, H. (2011, April 10). How Worried Are Consumers about Privacy? *TechCrunch*. Retrieved from <http://techcrunch.com/2011/04/10/how-worried-are-consumers-about-privacy/>
- Katz, C. (2001). Vagabond Capitalism and the Necessity of Social Reproduction. *Antipode*, 33(4).
- Katz, C. (2004). *Growing Up Global: Economic Restructuring and Children's Everyday Lives* (1st ed.). Minneapolis, MN: Univ Of Minnesota Press.

- Katz, C. (2005). Partners in Crime? Neoliberalism and the Production of New Political Subjectivities. *Antipode*, 37(3), 623–631.
- Keen, A. (2008). *The Cult of the Amateur: How blogs, MySpace, YouTube, and the rest of today's user-generated media are destroying our economy, our culture, and our values* (Reprint.). New York: Doubleday.
- King, S. (1996). Researching Internet Communities: Proposed Ethical Guidelines for the Reporting of Results. *The Information Society*, 12(2), 119–127.
- Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Kleinman, A., Das, V., & Lock, M. M. (Eds.). (1997). *Social Suffering* (1st ed.). Berkeley, CA: University of California Press.
- Knowles, J. (1977). The Responsibility of the Individual. *Daedalus*, 106, 57–80.
- Lanier, J. (2011). *You Are Not a Gadget: A Manifesto* (Reprint.). New York: Vintage.
- Latour, B. (2005). *Reassembling the Social: An Introduction to Actor-Network-Theory*. New York: Oxford University Press.
- Lefebvre, H. (1991). *The Production of Space* (1st ed.). Malden, MA: Blackwell.
- Lefebvre, H., Moore, G., & Elden, S. (2004). *Rhythmanalysis: Space, Time and Everyday Life* (1st ed.). New York: Continuum.
- Lenhart, A., & Fox, S. (2006). *Bloggers: A portrait of the internet's new storytellers*. Pew Internet & American Life Project. Retrieved from <http://www.pewinternet.org/Reports/2006/Bloggers/01-Summary-of-Findings.aspx>
- Levina, M. (2012). Our Data, Ourselves: Feminist Narratives of Empowerment in Health 2.0 Discourse. In Y. J. Oh & R. Gajjala (Eds.), *Cyberfeminism 2.0* (First printing.). New York: Peter Lang Publishing.
- Low, S. M. (1996). Spatializing culture: the social production and social construction of public space in Costa Rica. *American Ethnologist*, 23(4), 861–879.
- Low, S. M. (2009). Towards an anthropological theory of space and place. *Semiotica*, 2009(175).
- Low, Setha. 2013 (forthcoming). "Spatializing Culture: An Engaged Anthropological Approach to Space and Place." In Giesecking, Jen Jack, William Mangold, Cindi Katz, Setha Low, and Susan Saegert, ed. *People, Place and Space: A Reader*. New York: Routledge.
- Luik, J. E. (2010). Blogging as Empowerment: Self-presentation of bloggers in Surabaya, Indonesia. Conference or Workshop Item. Retrieved December 12, 2012, from <http://repository.petra.ac.id/15379/>
- Lupton, D. (24). *The imperative of health: public health and the regulated body*. 181 p.
- Mairs, N. (1996). *Carnal Acts* (2nd ed.). New York: Beacon Press.
- American Hospital Association. Management Advisory: A Patient's Bill of Rights. (1992, October 21).

Retrieved from http://www.patienttalk.info/AHA-Patient_Bill_of_Rights.htm

- Masum, H., Newmark, C., & Tovey, M. (2011). *The Reputation Society: How Online Opinions Are Reshaping the Offline World*. Cambridge, MA: MIT Press.
- McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies*, 25(2), 82–89.
- McLuhan, M. (1969). *The Gutenberg Galaxy*. New York: Signet.
- McNamara, K. (2007). *Blogging Breast Cancer: Language and Subjectivity in Women's Online Illness Narratives*. Retrieved from <http://cct.georgetown.edu/65545.html>
- Mendelsohn, J. (2010, March 12). Honey, Don't Bother Mommy. I'm Too Busy Building My Brand. *The New York Times*. Retrieved from <http://www.nytimes.com/2010/03/14/fashion/14moms.html>
- Metzl, J., Kirkland, A. (2010) *Against health: how health became the new morality*. New York: New York University Press.
- Meyrowitz, J. (1986). *No Sense of Place: The Impact of Electronic Media on Social Behavior* (1st Edition.). Oxford: Oxford University Press.
- Meyrowitz, J. (2004). The rise of glocality: new sense of place and identity in the global village. In *The global and the local in mobile communication: places, images, people, connections*. Hungarian Academy of Sciences, Budapest. Retrieved from http://www.fil.hu/mobil/2004/meyrowitz_webversion.doc
- Miller, C., & Shepherd, D. (2004). Blogging as Social Action: A Genre Analysis of the Weblog" Into the Blogosphere: Rhetoric, Community, and Culture of Weblogs. *Into the Blogosphere: Rhetoric, Community, and Culture of Weblogs*.
- Miller, E. A., & Pole, A. (2010). Diagnosis Blog: Checking Up on Health Blogs in the Blogosphere. *American Journal of Public Health*, 100(8), 1514–1519.
- Morgen, S. (2002). *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (1st ed.). Rutgers, NJ: Rutgers University Press.
- Morozov, E. (2011). *The Net Delusion: The Dark Side of Internet Freedom*. New York: Public Affairs.
- Nelson, Alan. (2002). Unequal treatment: confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, 94(8), 666–668.
- Nelson, Alondra. (2011). *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination*. Minneapolis, MN: University Of Minnesota Press.
- Orgad, S. (2005). *Storytelling Online: Talking Breast Cancer On The Internet*. New York: Peter Lang.
- Patton, T. O. (2006). Hey Girl, Am I More than My Hair?: African American Women and Their Struggles with Beauty, Body Image, and Hair. *NWSA Journal*, 18(2), 24–51.
- Pedersen, S., & Macafee, C. (2007). Gender Differences in British Blogging. *Journal of Computer-Mediated Communication*, 12(4). Retrieved from <http://jcmc.indiana.edu/vol12/issue4/pedersen.html>

- Pitts, V. (2004). Illness and Internet empowerment: writing and reading breast cancer in cyberspace. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*, 8(1), 33–59.
- Plant, S. (1997). *Zeros and Ones: Digital Women and the New Technoculture*. London: Fourth Estate.
- Porter, D. (1998). *Health, Civilization and the State: A History of Public Health from Ancient to Modern Times*. New York: Routledge.
- Powell, R. (2010). Good Mothers, Bad Mothers and Mommy Bloggers: Rhetorical Resistance and Fluid Subjectivities. *MP: An Online Feminist Journal*, 37–50.
- Rabinow, P. (1996). *Essays on the Anthropology of Reason* (1st ed.). Princeton, NJ: Princeton University Press.
- Rainie, L., & Wellman, B. (2012). *Networked: The New Social Operating System*. Cambridge, MA: The MIT Press.
- Ratliff, C. (2004, March 25). Whose Voices Get Heard? Gender Politics in the Blogosphere. *CultureCat: Rhetoric and Feminism*. Retrieved from <http://culturecat.net/node/303>
- Rheingold, H. (1993). *The Virtual Community: Homesteading on the Electronic Frontier* (Vol. Revised). Reading, PA: Addison-Wesley.
- Ritzer, G., & Jurgenson, N. (2010). Production, Consumption, Prosumption The nature of capitalism in the age of the digital “prosumer”. *Journal of Consumer Culture*, 10(1), 13–36.
- Robinson, K. M. (2001). Unsolicited Narratives from the Internet: A Rich Source of Qualitative Data. *Qualitative Health Research*, 11(5), 706–714.
- Rose, N. (1998). *Inventing Our Selves: Psychology, Power, and Personhood*. New York: Cambridge University Press.
- Rose, N. (2006). *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton, NJ: Princeton University Press.
- Rose, N., & Novas, C. (2002). *Biological Citizenship*. Retrieved from <http://webfirstlive.lse.ac.uk/sociology/pdf/RoseandNovasBiologicalCitizenship2002.pdf>
- Rothman, S. M., Raveis, V. H., Friedman, A., & Rothman, D. J. (2011). Health advocacy organizations and the pharmaceutical industry: an analysis of disclosure practices. *American journal of public health*, 101(4), 602–609.
- Sandaunet, A.-G. (2008). The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociology of health & illness*, 30(1), 131–144.
- Sarasohn-Kahn, J. (2008). *The wisdom of patients: Health care meets online social media. ihealth reports*. California HealthCare Foundation. Retrieved from <http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=133631>
- Sarbin, T. R. (1986). *Narrative psychology: the storied nature of human conduct*. Westport, CT: Praeger.

- Sassen, S. (2002). Towards a Sociology of Information Technology. *Current Sociology*, 50(3), 365.
- Scharf, B. (1999). Beyond Netiquette: The Ethics of Doing Naturalistic Discourse Research on the Internet. In S. Jones (Ed.), *Doing Internet Research*. London: SAGE Publications.
- Schmidt, H. (2007, July 7). Health Responsibility, the Left, and the Right. *Bioethics Forum*. Retrieved from <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=440>
- Shamir, R. (2008). The age of responsabilization: on market-embedded morality. *Economy and Society*, 37(1), 1–19.
- Siegel, L. (2008). *Against the Machine: Being Human in the Age of the Electronic Mob*. New York: Spiegel & Grau.
- Sixsmith, J., & Murray, C. D. (2001). Ethical issues in the documentary data analysis of Internet posts and archives. *Qualitative health research*, 11(3), 423–432.
- Smith, D. B. (2005). Racial And Ethnic Health Disparities And The Unfinished Civil Rights Agenda. *Health Affairs*, 24(2), 317–324.
- Smith, N., & Katz, C. (1993). Grounding Metaphor: Towards a Spatialized Politics. In M. Keith & S. Pile (Eds.), *Place and the Politics of Identity* (pp. 67–83). New York: Routledge.
- Soja, E. W. (1996). *Thirdspace: Journeys to Los Angeles and Other Real-and-Imagined Places*. Malden, MA: Blackwell.
- Starr, P. (1982). *The social transformation of American medicine*. New York: Basic Books.
- Stavrositu, C. (2007). *Technologies of Psychological Empowerment: The Role of Agency and Community in Blogging*. Philadelphia, PA: The Pennsylvania State University.
- Stavrositu, C., & Sundar, S. S. (2008). Can blogs empower women?: designing agency-enhancing and community-building interfaces. In *CHI '08 Extended Abstracts on Human Factors in Computing Systems* (pp. 2781–2786). New York: ACM.
- Stuedahl, D. (2010). Silences and Vulnerability in Participation. In P. Elovaara, J. Sefyrin, M.-B. Öhman, & C. Björkman (Eds.), *Travelling Thoughtfulness - feminist technoscience stories. (Festschrift in honour of Christina Mörtberg)* (pp. 167–183). Umeå University, Department of Informatics.
- Sweeney, B. (2013, March 18). How mommy bloggers make the car payment. *Crain's Chicago Business*. Retrieved April 23, 2013, from <http://www.chicagobusiness.com/article/20130316/ISSUE01/303169979/how-mommy-bloggers-make-the-car-payment>
- Technorati media. (2011). *State of the Blogosphere 2011*. Retrieved from <http://technorati.com/social-media/article/state-of-the-blogosphere-2011-introduction/>
- Thompson, G. (2007). Responsibility and neo-liberalism. *open Democracy: free thinking for the world*, [http://www.opendemocracy.net/article/responsibility_and_neo_liberalism\(1/30\)](http://www.opendemocracy.net/article/responsibility_and_neo_liberalism(1/30)). Retrieved from http://www.opendemocracy.net/article/responsibility_and_neo_liberalism
- Turkle, S. (2012). *Alone Together: Why We Expect More from Technology and Less from Each Other*. New York: Basic Books.

- Vilhauer, R. P. (2009). Perceived Benefits of Online Support Groups for Women with Metastatic Breast Cancer. *Women & health, 49*(5), 381–404.
- Walker, R. (2010, October 22). Mommy Blog Empowerment. *The New York Times*. Retrieved from <http://www.nytimes.com/2010/10/24/magazine/24FOB-Consumed-t.html>
- Walther, J. B. (2002). Research Ethics in Internet-Enabled Research: Human Subjects Issues and Methodological Myopia. *Ethics and Information Technology, 4*, 205–216.
- Wathen, C. N., & Harris, R. M. (2007). "I Try to Take Care of It Myself." How Rural Women Search for Health Information. *Qualitative health research, 17*(5), 639–651.
- Wolf, N. (2002). *The Beauty Myth: How Images of Beauty Are Used Against Women* (Reprint.). New York: Harper Perennial.
- Woo, J. (2006). The Right Not to be Identified: Privacy and Anonymity in the Interactive Media Environment. *New Media Society, 8*, 949–967.